

# Growth in the use of early intervention for psychosis services:

An opportunity to promote recovery  
amid concerns on health care  
sustainability

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# FOREWORD

Early intervention is a vital way of helping both to prevent, as well as maximise the chances of real recovery in those with diagnosed illness, in any field of medicine. The earlier the intervention, the better the outcomes achieved. While this case for early intervention is well-known and well-made, right across the globe policymakers and practitioners seeking to implement this approach in psychiatry have often had to contend with many common difficulties and barriers to action. These include a knowledge gap. The psychiatric profession must ensure that all leaders in psychiatry and mental health service provision have an appropriate level of knowledge, training and experience with preventive actions and early intervention for all mental health issues.

This report provides an overview of early intervention services for first episode psychosis in Europe and some other countries. It highlights the value of collecting experiences, data and other information to help provide an explanation for the different levels of development of services in different countries. The authors are correct in their assertion that “while early intervention services can be developed in very different health system structures, there are marked differences in service availability in the high-income countries examined in this report; moreover examples of services in low income country contexts remain rare.” Many of the strategies and recommendation that are put forward to strengthen services are also relevant to countries outside of Europe that have limited more limited resources.

Young people, who are at highest risk of psychosis in the general population, make up a substantial share of the population in many of the emerging economies in Asia and Africa. Health systems in these countries are poorly prepared to address mental health needs, with insufficient development of the most fundamental of health system resources and social supports. The argument for investing in development of early intervention services goes beyond health alone; it can help protect the most important asset of any low, middle or high income country, its educational and human capital. This report is essential reading for those looking to develop new strategies today to strengthen mental health services tomorrow.

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## SUMMARY

Psychotic disorders can have potentially life shattering consequences, with social and economic impacts for all of society. Early intervention to support people with psychosis can help to reduce the impact of the condition, reduce the risk of further (and often more debilitating) episodes and therefore increase the chance of better social and functional outcomes, such as completing education and staying in employment. Better outcomes and a positive societal return on investment are driven by three key components: (1) well-engaged health and other sector professionals, working collaboratively to achieve long-term outcome goals; (2) infrastructure supportive of early intervention services; and (3) the development of early intervention care pathways for people with psychosis and their families.

Multi-disciplinary early intervention services, working with a much lower caseload than conventional mental health services, have developed to reduce the duration of untreated first episode psychosis. This report points to well established networks of early intervention services, encouraging health systems to take notice and share messages of clinical and economic evidence, including benefits beyond the health care sector. These economic arguments have in fact often been influential in the expansion and mainstreaming of services in some countries. This is of particular interest, given the increasing pressure on health care providers to implement efficiency and service optimisation amid raising affordability concerns.

Governments and competent authorities can also play an important role in facilitating implementation by taking steps to monitor whether services are being delivered in line with accepted guidelines. Links with primary care, and the inclusion of physical health specialists within service teams, are likely to be particularly important to improving long term continuity of care and reduce the risks of poor physical health.

While early intervention services can be developed in very different health system structures, there are marked differences in service availability in the high-income countries examined in this report; moreover examples of services in low income country contexts remain rare. A number of recommendations which can help a policy dialogue to shape the care people with psychosis receive and help expand the availability of services in some countries, and sustain their provision in others, are made.

The report concludes that there is an opportunity to rethink care pathway models for psychosis, putting a greater emphasis on investment early intervention. Many health systems are under great financial pressure, which may make what are often perceived to be expensive specialist early intervention services vulnerable to cuts. In fact the financial pressures on health systems should be seen as an opportunity to make a compelling case for investment in early intervention; there is much unrealised potential to avoid more of the substantial lifelong costs associated with poor outcomes in psychosis through greater levels of investment.

# 1 INTRODUCTION

## 1.1 THE IMPACT OF PSYCHOSIS

The lifetime prevalence of psychosis is modest, affecting between 1% and 1.5% of the population. The most common diagnoses associated with psychosis are schizophrenia, schizophreniform disorder, schizoaffective disorder, bipolar disorder and major depression with psychotic features. These can be devastating diagnoses. Looking at schizophrenia alone, and despite its low prevalence, in high income countries for men aged between 15 and 49 schizophrenia is still the tenth ranked contributor to years-lived with disability (YLDs) – with an overall 11% increase in years lost compared with 1990 figures. It is also the 11th ranked contributor to YLDs for women in this age group in the developed world. Its impacts are also growing in the developing world where it ranks 13th for YLDs for men and women in the same age group – a 60% increase in years lost since 1990 (Institute for Health Metrics and Evaluation, 2013).

These psychotic disorders can have potentially life shattering consequences for people both living with these conditions and their families; furthermore there are social and economic impacts that fall on all of society. Perhaps most stark though of all these adverse consequences are the extraordinarily high levels of excess mortality seen over many decades in people with these disorders compared to the general population (Laursen, Nordentoft and Mortensen, 2014, Reininghaus et al., 2014). Even in Nordic countries with their good social welfare systems and few financial barriers to access to health care services, major differences in life expectancy can be found. Analysing the psychiatric hospital data of almost 300,000 people, men with recent onset schizophrenia spectrum disorders had lower life expectancies of between 15.5 years in Finland and 19.9 years in Sweden compared to the general population; comparable figures for women revealed a life expectancy difference of between 10.9 years in Finland and 17.3 years in Sweden (Nordentoft et al., 2013). Management of physical health problems is also exacerbated by the presence of psychotic disorders; further strengthening the argument for placing great emphasis on protecting the physical health of people experiencing first episode psychosis (McDaid and Park, 2015). The economic impacts of psychosis go well beyond health care systems, with more than two-thirds of the costs falling outside of health care systems (See Box 1). This reflects the enormous impact of psychosis on lifetime opportunities to participate in civil society, have families and enjoy good quality work and education. There are also substantive impacts on close family and friends who may have devote much time to providing support to people experiencing psychosis. Caregiving can also have impacts on their physical and psychological health.

#### Box 1: Some of the economic impacts of psychosis

- €94 billion – the annual cost of psychosis across 30 European countries in 2010. Including €29 billion in health care costs and €65 billion in productivity losses from time out of work (Olesen et al., 2012).
- In England alone the cost of schizophrenia estimated to be more than €16 billion; costs to the public purse of more than €7 billion (Andrew et al., 2012)
- Psychoses can at least double the costs of managing many chronic physical health problems (McDaid and Park, 2015).
- Psychoses can disrupt education, reducing long-term employment prospects (Knapp et al., 2014)
- Employment rates for people with psychoses are very low in Europe, often below 10% (Knapp et al., 2014).
- About 10% of all care costs fall on family caregivers in the UK and Ireland (Andrew et al., 2012, Behan, Kennelly and O'Callaghan, 2008)

## 1.2 EARLY INTERVENTION TO MEET THE CHALLENGE OF PSYCHOSIS

The severity of the impacts of psychosis led to a focus in mental health research on evaluating strategies to intervene as early as possible. The case for early intervention (EI) strategies for psychosis has been developing over more than 30 years, countering a fatalistic school of thought dating back to the pioneering work in the 19th century of Emile Kraepelin that saw these conditions as progressive and disabling (McGorry, Killackey and Yung, 2008).

In Melbourne in the mid 1980s the Royal Park Hospital began a programme of promising research on people with first episode psychosis leading to the opening of a specialist unit in 1990 (McGorry, 1993). Subsequently a growing number of researchers, outside as well as in Australia, have argued for early intervention strategies (Birchwood and Macmillan, 1993, Birchwood, McGorry and Jackson, 1997, Birchwood, Todd and Jackson, 1998, McGlashan, 1998, Linszen et al., 1998, McGorry et al., 2009).

The evidence base on the effectiveness of EI around the globe continues to grow (Secher et al., 2014, Hegelstad et al., 2012, McGorry et al., 2009, Marshall et al., 2014, Marshall and Rathbone, 2011, Larsen et al., 2011). Some evidence on their cost effectiveness has also been published (Hastrup et al., 2013, Park, McCrone and Knapp, 2014, McCrone et al., 2013, Wong et al., 2011, McCrone et al., 2010, Mihalopoulos et al., 2009, Ising et al., 2015).

As a result today researchers know that most first episodes of psychosis are usually preceded by early signs and symptoms (known as the prodromal period). Identifying these warning signs and intervening early to support people with psychosis may help to reduce the impact of the condition, decrease the risk of further (and often more debilitating) episodes and therefore increase the chance of better social and functional outcomes, such as completing education and staying in employment.

EI potentially might also help reduce the risk of self-harm. One meta analysis of 18 studies reported that 18.4% of people experiencing psychosis had deliberately self-harmed prior to receiving treatment; moreover the risk of self harm rose with increased duration of untreated psychosis (DUP) (Challis et al., 2013). An English study suggested that between 10% and 11% of individuals self-harm between the onset of symptoms and receipt of treatment (Harvey et al., 2008). EI, if successful, might also reduce the risk of homicide and other violent acts. One review reported that 39% of homicides and 38% of all assaults by people with psychosis occur during the first episode of psychosis (although these events remain rare in the population as a whole) (Nielsen et al., 2012).

Furthermore, a greater focus on actions to support people at ultra high risk of psychosis may also have the potential not only to delay but also reduce the future likelihood that high risk individuals progress to psychosis, although this research is still at an early phase (Stafford et al., 2013, Heinssen and Insel, 2015, van der Gaag et al., 2013, McFarlane et al., 2015).

Despite this growth in the evidence base, with recognition that EI services can be an important component of the mental health system and examples of implementation in a number of countries, it has been argued that these services are still “not yet a broadly accepted or consistent feature of care in most developed countries” (Addington, 2011). This may be because services are complex, typically involving many different health care professionals working intensively with a much lower caseload than conventional mental health services, thus making them expensive to implement and potentially vulnerable to budget cuts in times of austerity.

There is a significant gap in what is known about the development of EI services outside of countries that where the initial research has been undertaken, such as Australia, Canada, England and Denmark. There has also been little discussion of health system factors that either facilitate or impede the development of EI services in all countries. It is these gaps in the evidence that this review seeks to address.

## 2 AIMS

The primary aim of this review is to provide a snapshot of the availability of EI services for psychosis in selected European countries that cover different funding and health system structures: predominantly tax funded systems ( England, Denmark, Norway, Italy and Spain); mixed tax and social health insurance systems (France and Ireland) and social health insurance systems (Germany). These findings are also put within the context of what is known about the availability of these services in a global context, focusing on experience in the largely publicly funded health care systems found in Australia and Canada.

The review is not an attempt to identify all EI services in these countries, nor does it assess the effectiveness of these services, but instead looks at their evolution, current status and innovation. For instance, it considers how the maturity and availability of EI services may be associated with the way in which health care services are funded, as well as with the availability of existing health and other public service infrastructure. The latter includes exploring links with primary care and non-mental health specialist services. It also looks at the complexity of EI services and how these compare with recommendations on key components of EI care.

Economic arguments potentially can be very important in strengthening the case for investment in services that might be perceived in some countries as an unnecessary luxury. Although a number of economic evaluations of early intervention services have been published, most of these have been in the UK<sup>1</sup> and Australia. Another aim was therefore to look to see whether EI services in Europe (and in particular beyond the UK) have been subject to economic evaluation and to consider the scope for building/expanding the existing evidence base through the development of economic models.

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<sup>1</sup> We focus in this report mainly on services in England rather than the UK as a whole; early intervention services are also found in the other three countries of the UK.

## 3 METHODS

A systematic literature review to identify early intervention services was conducted covering the time period between January 1 2004 and 31 August 2014 and examining the Medline, CINAHL, Psychinfo and Global health databases. As well as these databases, a number of different sources of information were explored and triangulated. These have included published papers, websites, You Tube clips and other video documentation.

### 3.1 THE CONCEPT OF EARLY INTERVENTION

Firstly we need to define what we mean by early intervention, as there is a lack of consistency in the use of the concept of early intervention by different authors and mental health systems. Our definition of this concept is set out in Box 2. It broadly consists of two elements: early detection (ED) services used during the prodromal period (period of disruption prior to the onset of illness) to prevent or delay the onset of psychosis<sup>2</sup>, and early intervention (EI) services that deliver intensive treatment services

#### Box 2: Concept: early intervention for first episode psychosis

Early intervention for individuals of any age experiencing a first episode psychosis can consist of two principle components that may often be delivered by a single service:

- Early detection services (ED): specific actions taken during the prodromal phase of illness to prevent or delay the onset of psychosis in individuals identified as being at high risk.
- Early intervention services (EI): actions designed specifically for delivery during the first episode of identifiable psychosis ( including schizophrenia, schizoaffective disorder, schizophreniform disorder, delusional disorder and brief psychotic disorder), with a view to reducing the duration of untreated psychosis (DUP), potentially reducing the severity and impact of the illness and improving prospects for recovery.

<sup>2</sup> Here the term psychosis is assumed to cover a number of different disorders including schizophrenia, schizoaffective disorder, schizophreniform disorder, delusional disorder and brief psychotic disorder

through multi-disciplinary teams specifically for individuals experiencing a first episode of identifiable psychosis, with a view to reducing the duration of untreated psychosis (DUP) and thereby reducing some adverse impacts. In many cases EI and ED functions will be integrated into one early intervention service.

### 3.1.1 Age of population

As Box 2 indicates, the concept of early intervention for first episode psychosis is not specifically related to age, although as most first episode psychoses are seen in people under the age of 40 (known as early onset psychosis) many services are specifically tailored for younger people. We are also interested in the provision of services for people who experience first episode psychosis between the ages of 40 and 65 (late onset psychosis). Some individuals who are over 65 will also experience very late onset of psychosis; we have excluded services for these people from our analysis as services for older people may be structured in a different way to those for adults of working age and the underlying cause of any psychosis may be related to dementia and delirium.

## 3.2 SCREENING PROCESS

Abstracts were screened; those that indicated they were about early intervention and/or early detection programmes for first episode psychosis in our countries of interest were then screened in full text to see if they did indeed describe an EI or ED service or provide a link to a service website. In addition, we looked at papers that described issues around pathways to care in our country contexts, including for example work conducted as part of the EPOS (European Prediction of Psychosis Study) (von Reventlow et al., 2014).

There were no language restrictions in our search but in some cases we pragmatically relied on automatic web page translation services to identify basic information about some services. A Google search was also undertaken to identify further information on named services, including video material, as well as to look for EI and ED services in our selected countries. In addition we also looked at the websites of member organisations listed on the website of the International Early Psychosis Association (IEPA) website, and screened all abstracts submitted to the most recent IEPA international conference on early psychosis that took place in Tokyo from 17th to 19th November 2014. A handsearch of all issues of the journal *Early Intervention in Psychiatry* including early on-line publications was also performed. The abstracts of relevant cited references that were mentioned in any of the published papers were also examined; again if they appeared to indicate an EI service we obtained the full text.

### 3.3 DESCRIBING INTERVENTIONS

Many published evaluations of interventions, it has been argued, have 'neither specified nor measured the components of care provided in the experimental and treatment-as-usual arms'(Addington et al., 2013). This review sought to document the key components of the EI services that were identified. A pragmatic approach was taken to doing this, relying specifically on descriptions in published papers and on service websites to identify the duration of treatments, eligibility criteria, referral pathways and sources of funding. Our approach took as a starting point published reviews and performance measures highlighting essential evidence-based elements of first episode psychosis services in the USA and Canada in particular (Addington et al., 2013, Addington, 2011, Nolin et al., 2014). Box 3 lists the different programme components that we documented. Given resource and time constraints we did not map all services

#### Box 3: Key components of early intervention programmes

Individual and/or group cognitive behavioural therapy

Individual/group psychosocial therapies

Education support

Employment support

Family interventions/therapy

Support for families

Pharmaceutical therapy

Day hospital

Physical activity/sports

Health advice (nutrition, smoking, alcohol, substances)

Peer support

Occupational therapy

Art/music/drama/yoga

Recreational group activities

Cognitive Remediation Therapy

Life/social skills training

Online/mHealth digital support

in England, given that more than 150 EI teams were identified. Instead information on a number of geographically dispersed EI services was documented. We also documented some examples of services in the other three countries of the UK. We triangulated information on country/ programme experience with relevant information from other overview of EI services (De Maio et al., 2015), as well as personal correspondence with some study authors connected with some of the early intervention services that we identified. A separate annex to this report provides an overview of the characteristics of services covered.

## 4 RESULTS

### 4.1 OVERVIEW

In most countries in Europe, and indeed around the globe, early intervention services remain an exception rather than a standard component of mental health services. Outside of Europe services are most developed in Australia, Canada, New Zealand, the USA, Singapore, Hong Kong and Japan. In Europe they are most well established in the UK (England) and Denmark, countries that have largely tax funded health care systems with few financial barriers to access at the point of use. EI services are all available in most cantons in Switzerland, but it is probably only in England where there is a sufficient geographically dispersed supply of EI services to meet demand across an entire country, although as the English experience described in this section indicates, the potential population that can benefit from these services may be greater than original epidemiological estimates that have been used to plan for service development.

The strength of EI services in different countries does not, however appear, to simply be a function of the level of funding allocation to mental health – countries such as France and Germany have comparable levels of mental health funding to England but the availability of EI services is much more limited. The way in which health care systems may play a more prominent role – countries with more developed EI services all appear to be countries in which primary care doctors are strong gatekeepers to secondary specialist health care services. Countries where EI services are gaining acceptance and expanding, such as Italy, also have a strong focus on primary care, as well as an ethos on community rather than hospital oriented delivery of mental health services. Equally in Spain where primary care is strong and services are largely tax funded, although EI services are sporadic and often reliant on research rather than health system funding, there appears to be some consensus among clinicians and the governments of some autonomous communities that EI services should be an important component of service provision. Schizophrenia guidelines referring to EI services are available in all of these countries. It is perhaps also not insignificant that Denmark, England and Norway have been at the forefront of research on the organisation of early intervention services in Europe; robust and positive long-term evaluation of EI pilot initiatives has helped enhance the credibility of the EI in these countries.

Champions of the development of EI services have also been crucial to the development of services. Globally one can point to the work of Professor Pat McGorry and colleagues in Australia in being a catalyst for investment in services; in England strong non governmental organisations that were effective in engaging with politicians, civil servants, clinicians and the media raised the issue, as for instance seen with the

Figure 1: Rethink 'Getting help early' – campaign slogan late 1990s



Source: (IRIS, 2012)

English charity Rethink Mental Illness' Getting Help Early Campaign in the late 1990s (Figure 1). In an English context health economic evidence, both from the UK and other countries such as Australia, suggesting that early intervention can be cost effective has been influential at national policy making level. Health economic evidence in England is seen as one crucial element of making evidence informed decisions in the health policy field, particularly after the establishment of NICE (now known as the National Institute for Health and Care Excellence) in 1999. These evidence based arguments have also been a key element in advocacy that has supported the expansion of EI services in Denmark (Nordentoft et al., 2015). This section now goes on to describe how EI services have developed in a number of different European countries.

## 4.2 ENGLAND

In the UK following devolution in 1999, health care became a responsibility of the governments of the four constituent countries of the UK and policies have increasingly diverged ever since. Our analysis therefore focuses largely on experience in the largest of the four countries, England. While early intervention in psychosis as an approach, originated in Australia, the National Health Service (NHS) in England was an early adopter, with some of the first services piloted and evaluated in the English West

Midlands in the mid 1990s (Lester et al., 2009, Marshall et al., 2014). Increased campaigning on the lack of early help for people with mental health problems, evidence on impact in the West Midlands, as well evaluative evidence from Australia and elsewhere, coupled with an increased focus on mental health following a change in government in 1997, all acted as catalysts for the substantial investment in EI teams that was to follow. The last 15 years of mental health policy in England have seen the publication of a raft of policy documents and national strategies. All of these mental health strategy documents have acknowledged the importance of EI services (Department of Health, 1999, Department of Health, 2000, HM Government, 2009, HM Government, 2011).

By far the most extensive network of EI services in Europe are to be found in England. In 2000 the government's NHS Plan stated that 50 EI services would be established to provide treatment and active support in the community to young people and their families; the aim was to provide services to 7,500 young people experiencing a first episode of psychosis each year by 2004 (Department of Health, 2000). Early intervention services are now to be found in most local health service catchment areas in the country; each service may have multiple teams in operation and overall there were more than 150 teams operating in 2014, supporting about 10,000 people per year (Rethink Mental Illness, 2014). This represents a considerable proliferation of services since they first started to appear as shown by Figures 2 and 3.

Figure 2: Early Intervention Service Provision in England in 2003



- 32 programmes across England in 2003
- Only one programme had activities to support social functioning
- Teams focused on pharmaceutical, psychological and family therapy

Data from North East Public Health Observatory, 2003

Figure 3: Early Intervention Services in England in 2014



- Over 150 EI service locations across England in 2014
- Focus also on housing, employment, education, physical activity, supporting families
- Many teams include vocational specialists, specialist advice on housing, benefits

Note: for practical purposes not all individual teams within a CCG shown on map

Initially, each of the planned 50 early intervention services was intended to cover a catchment area of roughly one million and have a new caseload of about 150 cases a year, thus typically serving a population of about 450 15–35 year olds (Joseph and Birchwood, 2005). While team size could vary, keyworkers were expected to manage an active case-load of about 15 cases; much lower caseloads than in conventional community mental health teams (Lester et al., 2009).

In practice as teams have developed there has been a considerable variation in geographical size of catchment areas covered by EI services. For instance the Lancashire Early Intervention Service, operates using a 'hub and spoke' model – in addition to the hub which includes administrative as well as clinical services, there are three teams, covering a total population in excess of 1.5 million (Lancashire Early Intervention Service, 2015).

All referrals are subject to initial assessment to ensure that they potentially meet the criteria for early intervention services. In most cases young people referred to an EI team are likely to be presenting for the first time to mental health services, and will not have yet received any antipsychotic treatment. These referrals can come from health and social care professionals, but also from other professionals and agencies such as

#### Box 4: Financing a local EI service: experience in Worcestershire

Worcestershire Health and Social Care Trust (WHSCT) runs an early intervention service consisting of two teams with a catchment area of about 560,000 population and covers residents in the Clinical Commissioning Group areas of South Worcestershire, Redditch and Bromsgrove, and Wyre Forest.

The service has been funded through a block contract with the CCGs for the provision of all mental health services including EI provision. For example, in the two year period to April 2013 the EI service block contract assumed that there would be up to 6,771 contacts per annum at a cost per contact of £136.68, with an expected annual contract value of £925,460 (Worcestershire Health and Social Care Trust, 2010).

teachers and school nurses, employment service providers, the police and other criminal justice agencies, as well as youth and social care services.

Teams are in theory similar in terms of their core elements, being multi-disciplinary in nature consisting of psychiatrists, psychologists, community mental health nurses, social workers and support workers. As Box 4 illustrates funding has largely been through fixed contracts which have specified maximum levels of funding linked to activity rates. Typical services that should be found in most early intervention teams not only include medications, psychological and family therapies, but also physical health care support, help in maintaining participation in education or with employment, and support for families. Care and support is usually provided for at least three and perhaps up to five years. Early detection services are sometimes embedded into the service; these are targeted at people who may be at risk of psychosis, and showing early low level signs of psychosis. They tend to be provided for between six and twelve months.

Services are usually provided in locations which are accessible to people across the community. This will include within service users homes, primary and secondary care settings, (including surgeries, health centres, community mental health teams and wards), community locations and other suitable settings which can provide a clinically effective and safe environment. Links with conventional community mental health teams are retained if individuals have previously been in contact with these teams. EI teams will also co-ordinate with other specialist psychiatric teams that deliver care in service users own homes (home treatment/crisis resolution treatment teams) to reduce the risk of relapse.

#### 4.2.1 Development of national standards on waiting times

Until recently there were no national standards on waiting time for mental health services, in contrast to long standing maximum waiting times for physical health problems. This situation is now changing. Quality standards from the National Institute for Health and Care Excellence (NICE) published in February 2015 recommended that *“adults with a first episode of psychosis start treatment in early intervention in psychosis services within two weeks of referral”* (National Institute for Health and Care Excellence, 2015) Subsequently with earmarked funding, the Coalition government announced plans for waiting time standards in April 2015 which if implemented as planned should mean that more than 50% of people experiencing a first episode of psychosis will be treated within two weeks of contact with mental health services (Department of Health, 2014) These two week waiting time standards were reaffirmed by the new Conservative government, with new Minister responsible for mental health, Alastair Burt, indicating that they were one of three key issues, (along with child mental health and crisis care) that the government is pursuing to achieve parity with physical health services (Burt, 2015). It has been up to local service commissioners to agree service improvement plans as part of their 2015/2016 contracts with mental health service providers, setting out how providers will prepare for and implement the new standards during 2015/16 and achieve them on an ongoing basis from 1 April 2016 (NHS England, 2015). At a national level systems are also being set up to develop resources to support and monitor implementation. Therefore, it will be some time before it will be possible to assess whether this process has been successful, particularly given the pressures on both local CCG health budgets and national training and support infrastructure.

#### 4.2.2 Funding pressures

Mental health budgets have come under pressure in England, but obtaining accurate data to explore whether spending on EI services has reduced is not easy; this now must be done at local level as data has not been collected centrally on mental health expenditure since 2012. In a written response to a Parliamentary question from Andrew Gwynne (23 March 2015) on spending on psychosis services in England, the then Minister for Health and Care, Norman Lamb, stated *“we do not centrally hold information on the amount of funding that was allocated to early intervention services for psychosis and crisis care in each year since 2009/10.”* He did though add that *“we have identified £33 million additional spending in the current year to support people in mental health crisis, and to boost early intervention services, that help some of the most vulnerable young people in the country to get well and stay well”* (Lamb, 2015).

While this promise of some increased funding appears encouraging, professionals working in the EI field have been more pessimistic. A survey undertaken by a leading mental health charity and the IRIS network of mental health professionals that support the promotion of early intervention in psychosis (Rethink Mental Illness, 2014), stated

that the services have reached a tipping point, where critical additional investment is needed to maintain services – some teams have been disbanded and others subsumed into conventional community mental health teams. The survey also found that physical health, employment and training, and social skills services have been most vulnerable to cuts.

One commentator noted that this *“survey of 96 of 125 early intervention psychosis services (EIP) in England revealed that 50% had seen their budgets cut in the last year. More than half of EIP services had lost staff (58%) and almost a third (31%) said that their caseloads had exceeded recommended levels. Some teams had been disbanded entirely, while others had seen their functions absorbed into community mental health teams”* (McNicoll, 2014b).

The challenge is twofold: at a time of real terms decreases in mental health expenditure, there has been an increase in unfilled posts in some teams, and/or pressure on EI teams to expand their roles in view of tight resources to provide support for other client groups. A reduction in the availability of services is likely to increase the chance of delays in access to support and treatment, with all the potential adverse consequences for health and other sectors. An independent taskforce on mental health (commissioned by the opposition Labour Party) recently warned “existing EI services should not be cut, as this not only harms health outcomes but increases NHS costs” (Taskforce on Mental Health in Society, 2015).

However, the impacts of a tight funding environment on the functioning of EI services are not a new phenomenon in England; even ten years ago where funding for health care was increasing significantly this did not necessarily translate into funding for EI services. A detailed qualitative analysis involving interviews with a wide range of health commissioners, EI team members and service users looked at some of the challenges to developing EI services in the English West Midlands between 2004 and 2006 (Lester et al., 2009). Maintaining an active caseload of 15 clients per keyworker was found to be important to securing continuing funding, putting much pressure on staff. Funding pressures also had an impact on access to services: one EI service reduced the upper age limit for eligibility, while another supported service users for less than the intended three years and two others established waiting lists for services. Some EI services also sought to reduce resource constraints by co-locating with community mental health teams or by forming delivery partnerships with other organisations.

### 4.3 DENMARK

Like England, Denmark has one of the better funded health care systems in Europe, spending about 10% of GDP on health. Funds are largely raised through taxation and the primary care system is strong. The country also benefits from an excellent electronic health record system making long-term follow-up of many different health

#### Box 5: The OPUS Early Intervention Programme

OPUS is a modified assertive community treatment programme including appropriate pharmacological, psychoeducational and family therapy, as well as life skills and problem solving training. Assertive action is taken to reach individuals to make an assessment, including home visits. OPUS has supported service users for up to two years. Each multi-disciplinary OPUS team contains between 8 and 12 staff, including a psychiatrist, psychologist, social worker and occupational therapist. The staff to client ratio is 1:10, much lower than that seen in standard community mental health teams in Denmark which have staff: client ratios varying between 1:20 and 1:30 (Nordentoft et al., 2015).

Operating five days per week, client can receive help with social and financial support in terms of applying for social benefits, housing, education, jobs, and social activities. Teams coordinate with primary and somatic care services, as well as with other agencies such as social welfare organisations, and even help to deal with the challenges of being sucked into financial debt

interventions much more feasible than in many other countries. Data linkage systems also allow impacts beyond health such as participation in employment to be considered.

Early intervention services can now be found in all five regions of Denmark, in part being justified through positive long-term evaluation of EI services in the country through the OPUS and TIPs studies. The latter was largely conducted in Norway, but included one early intervention and detection service based at Roskilde in Denmark and is discussed in section 4.7. The OPUS study evaluated the impact of a modified assertive community treatment programme (See Box 5) for people experiencing a first episode of psychosis, aged between 18 and 45 (Jorgensen et al., 2000). Individuals with possible psychotic symptoms were referred to detection teams set up in Copenhagen and Aarhus. A one off educational programme run by these detection teams was targeted at primary and social care services, schools, and clubs for young people to help raise awareness of the programme.

#### 4.3.1 Evaluation of OPUS

OPUS has been subject to both clinical and economic evaluation. Initial analysis of data from 547 service users in the trial reported improved clinical outcomes and satisfaction with treatment at both one and two years follow-up periods (Petersen et al., 2005). At two-year follow-up a significant improvement in mean Global Assessment of Functioning (GAF) scores was found (55.16, s.d.=15.15), compared with the standard

**Box 6. OPUS: economic analysis**

Economic evaluation at five-year follow-up suggested that the intervention had a 93% chance of having lower costs and better outcomes than treatment as usual ; costs were lower in each of the five years, being significantly lower in year four by a mean of €7,407 per person, however the difference in mean five year costs between the OPUS and control groups, €111,924 versus €137,638 was not significant. There was significantly less need for supported housing in the OPUS group (Hastrup et al., 2013); (57 versus 102 days  $p < 0.05$ ); days of hospitalisation were still lower although this difference was no longer significant (Bertelsen et al., 2008, Nordentoft et al., 2010).

At 10-year follow-up, relying on data from 63% of participants, the treatment group still had a lower need for supported housing (Secher et al., 2014), potentially avoiding some further costs to Danish taxpayers, although these differences were no longer statistically significant, except for days spent in hostels for the homeless.

treatment group (51.13, s.d.=15.92). After two years, people in the integrated treatment arm also had a significant reduction in psychotic symptoms ( $p=0.02$ ) and in negative symptoms ( $p < 0.001$ ) (Petersen et al., 2005), although the absence of a permanent active information campaign may have limited the ability of the programmes to reduce DUP (Nordentoft et al., 2008). The proportion of referrals from primary care and other sources outside psychiatric departments ranged from 11.7% to 15.2% (Nordentoft et al., 2008). At two-year follow-up, people in the OPUS group on average spent significantly less days in hospital than those in the standard treatment group (96 days versus 123 days, ( $p = 0.05$ ) (Bertelsen et al., 2008).

At five-year follow-up the positive benefits of treatment on psychosis were no longer visible, but there were other positive impacts that potentially could have economic benefits. The economic evaluation results were also favourable (Box 6).

**4.3.2 EI service expansion in Denmark**

OPUS was funded initially as a research grant rather than from public funds, but when funding ran out after five years the Copenhagen service was then funded by the capital's health service provider and further research projects have been conducted, proving more funding support. Services were initially provided just in Copenhagen and Aarhus but have since been expanded, due in part, to positive clinical and economic evaluation. The OPUS approach was recommended in guidance documents and at national level grants were made available by Parliament. Regional health authorities

could then apply for funds to help to establish new services. While half of all the OPUS teams are in the Capital (Copenhagen) Region, teams are now found in all five regions of Denmark:

*“in 1998, there was one team in Aarhus and two small teams in Copenhagen, with a total of 22 employees; at the beginning of 2013, there were 20 teams with a total of more than 200 employees, located in all five Danish regions and disseminated all over the country”* (Nordentoft et al., 2015).

New OPUS Programmes such as those in Odense, Aabenraa and Esbjerg, have been involved in a trial looking at adjunct cognitive adaptation training to help mitigate cognitive deficits associated with schizophrenia (with inconclusive results) (Hansen et al., 2012, Hansen et al., 2013). In the Jutland Region teams can now be found in Brønderslev and Aalborg. There is also a team at Kolding in Southern Denmark. In the Central Denmark region OPUS teams at Risskov, Horsens and Herning also applied for additional government funding to extend their target population to include clients over the age of 30 (Central Denmark Region, 2009).

Funding was also provided to evaluate extending the duration of OPUS to five years (Melau et al., 2011). This follow-up trial, OPUS-II, has been funded by the Danish Agency for Science Technology and Innovation, involving 6 OPUS teams in the Capital and Central Denmark Regions (Melau et al., 2011).

Other research projects involving early intervention teams can also be identified in Denmark, for instance evaluating adjunct cognitive remediation therapy use by early intervention teams (Ostergaard Christensen et al., 2014). An early detection team in Zealand was also set up in 2012 and is part of the TOPS study (Jansen et al., 2015); this is looking at pathways to care and the duration of untreated psychosis prior to the establishment of a detection team (Hastrup, Haahr and Simonsen, 2014).

However despite the expansion of EI services, the OPUS research team continue to argue that capacity in the country is still insufficient to support clinical need and services need to be expanded by at least 50% (Nordentoft et al., 2015). This not only includes expanding the duration of existing services potentially to 5 years to optimise their effectiveness, but also to have a greater focus within services on promoting healthy lifestyles and physical health and catering to the needs of service users with children.

#### 4.4 FRANCE

Our review suggests that there has been little development of specialist early intervention services for people with psychosis in France, even after a study published a decade ago in the Bordeaux region found that the majority of people with psychosis do not come into contact with specialist services early in the course of the illness

**Box 7: Samsah early intervention service in Prepsy, Ile de France, Paris**

The early intervention service in Prepsy includes a psychiatrist, psychiatric nurses and social workers and its main aim is to reduce access time to appropriate specialist care services for people with psychosis, as well as improve links and support for the primary care doctors of people with first episode psychosis.

The team handles about 300 clients per year and usually supports them for a minimum of two years. The service is funded by the City of Paris and Social Security.

(Cougnaud et al., 2006). There remains a strong focus on hospital based care and traditional mental health centres in the French mental health system (Verdoux, 2007), with few and home-delivered mobile services. Some multi-disciplinary mental health networks can be found in the country, but they do not appear to have a strong focus on early detection or early intervention for first episode psychosis.

We identified one early detection service, relying on perennial short term grants and state funding, that has been operating in Paris for a decade and serving a catchment area covering 3 million people (Gozlan, Acef and Petitqueux-Glaser, 2009) (Box 7).

There is also a network of psychiatric hospital based schizophrenia expert centres that have been developed by the non-governmental organisation Fondation Fondamental. They do not have any detection or strong outreach focus but instead assess and diagnose people with suspected psychosis referred from other health professionals and then recommend a course of action to patients, their families and health professionals. Partly financed through an initial state grant, the NGO has to raise additional funds through public donations and participation in national and international research projects.

A major structural limitation in France, is that one of the fundamental evidence based components of EI programmes, psychological therapy, is not generally reimbursed through the public health care system, and thus is not widely available (Fondation Fondamental, 2015). In general, the approach to treatment of first episodes of psychosis in France does not appear to take a multi-method approach and seems to rely on antipsychotic therapy alone (Vacheron and Caroli, 2008). The small pathway study in Bordeaux indicated that only 1% of 79 people with a first episode of psychosis were receiving support from psychologist and no-one had been in contact with a primary care doctor (Cougnaud et al., 2006). More recently a survey in Brittany reported that primary care doctors do not have good knowledge of the detection and early management of psychosis (Le Galudec et al., 2014).

## 4.5 GERMANY

Health services in Germany are funded largely through a mixture of social and private health insurance; primary care services do not act as gatekeepers to specialist care services. EI services are rare; the focus has been more on early detection services to identify people at risk of psychosis rather than creating multi-disciplinary multi-methods early intervention programmes for those already experiencing probable first episode psychosis (Wölwer et al., 2013). Where services are available, the emphasis has been on research rather than the routine delivery of early intervention services through the German Schizophrenia Research Network.

The network has encouraged collaboration between university departments of psychiatry, hospitals and networks of general practitioners (Wölwer et al., 2006) and the network brings together university hospital-based programmes in cities such as Berlin, Bochum, Bonn, Dresden, Dusseldorf and Munich (Leopold et al., 2013, Bechdolf et al., 2012). Perhaps the most well known programme is the Cologne early detection centre that has been operating since 1997 (Schultze-Lutter et al., 2008). This service is focused on providing advice on the types of treatment that can be provided rather than being an integrated service, but some services such as cognitive behavioural therapy are provided.

Through the Research Network, drug therapies and cognitive behavioural therapy in the prodromal phase of psychosis have been evaluated (Ruhmann et al., 2005, Bechdolf et al., 2005), and more recently a multi-centre controlled trial in four early detection centres reported that an integrated psychological intervention, combining individual cognitive-behavioural therapy, group skills training, cognitive remediation and multifamily psychoeducation was superior to conventional supportive counselling in the prevention of psychosis in an identified early prodromal risk population (Bechdolf et al., 2012).

A major challenge has been the way in which the health care system has been organised, including the way in which mental health services have been funded. Inflexibility in payment tariffs for mental health services have acted as barriers to the development of integrated multidisciplinary and community oriented approaches to early intervention for psychosis. However, new legal structures within the health system in Germany for *Integrierte Versorgung* (Integrated Care) and *Modellprojekte* (Model projects) allow for funding of more integrated hospital and community care. They have been identified as “as a starting point to implement early detection and intervention in routine care in Germany. Establishing early detection and intervention of psychosis in Germany could call upon early detection and intervention centres which have been established as part of [the German Schizophrenia] research framework” (Muller, Laier and Bechdolf, 2014).

Integrated care networks for the treatment of mental illness have been growing in Germany. One example of this can be seen from the AOK social insurance fund in

Germany which funds integrated care networks for the management of established schizophrenia in people over 18 in Lower Saxony (AOK, 2015). These services could, in principle, be extended to have a specific focus on first episode psychosis.

## 4.6 ITALY

Italy has a strong and long standing focus on services delivered through community mental health centres. All mental health hospitals have been closed, including forensic hospitals. The system is funded mainly through taxation, and like Spain, mental health services are decentralised to local regions where the composition of mental health services varies considerably. GP referrals are not usually necessary to come into contact with community mental health services. The development of early intervention services within this context has been limited, with existing centres handling very small numbers of clients.

One recent survey targeted at adult public mental health service directors in Italy found that about 1 in 4 local health service regions claim to have some form of basic EI service, with 90% of these services including psychotherapy and psychoeducation. Most of these 44 EI services are in central and northern Italy, but they do not always conform to national guidance on psychosis and have variable staff complements and opening hours. All centres appear to provide multiple interventions including psychological therapies and vocational support.

On the basis of this survey the authors concluded that the availability of early intervention in psychosis services is growing slowly, but that the number of service users was very low. This was despite the publication of national guidelines endorsing early intervention for schizophrenia in 2007 (De Masi et al., 2008). They thus argued for more efforts to influence policy making and to ensure better financial support to help in the establishment of EI services in poorer parts of the country. They also pointed to poor outcome measurement and called for measures to ensure the routine evaluation of EI services to build up a stronger local evidence base (Cocchi et al., 2014a, Ghio et al., 2012, Cocchi et al., 2015). Poor collaboration between referral organisations and EI services has been highlighted as a barrier to continuity of care (Cocchi et al., 2015).

The most longstanding and established service, the Programma2000 in Milan, has been discussed in a number of academic papers (Meneghelli, Cocchi and Preti, 2010, Cocchi, Meneghelli and Preti, 2008) (Box 8). One catalyst for the expansion of EI services was a set of Italian national guidelines endorsing early intervention for schizophrenia in 2007 (De Masi et al., 2008). There has also been an EI service in Rome since 2004. An early detection service (SMILE) for all types of mental health problems, including detection of psychosis was also established in L'Aquila in 2005; it did not though have a specific early intervention team (Pollice et al., 2007, Ussorio et al., 2015). The service continued to operate even after the devastating earthquake in

**Box 8: Programma 2000, Milan**

[www.programma2000.org/it/programma2000](http://www.programma2000.org/it/programma2000)

Established in 1999, serving a catchment area of 200,000, and focused on early detection, diagnosis and intervention for people aged 17 to 30 with or at high risk of psychosis. Open nine hours every weekday it has one full time equivalent psychiatrist, several clinical psychologists and an employment professional. It receives around 60 referrals and takes on about 20 cases per year. Care can last up to five years.

A package of care can include pharmacological treatment, various forms of psychoeducational and cognitive-behavioural psychotherapy, individual family psychoeducation and support, therapeutic group activities (e.g. anxiety management, assertive and problem-solving training, and substance-abuse prevention), social activities (e.g. computer-training, music and language courses), as well as vocational rehabilitation and intensive personal school support.

the town in 2009, but understandably its focus has changed to deal with the aftermath of this natural disaster (Pollice et al., 2012). More recently a government funded project has been used to provide training and piloting of additional early intervention initiatives in Milan, Rome and Catanzaro (Cocchi et al., 2015).

Other examples of newer services in the north of Italy include an early detection and intervention service in the Desio area north of Milan with a catchment area of 230,000 (Cocchi et al., 2014b). Another early intervention programme TempoZero, covering a catchment area in Alpine Italy of 140,000 initially focused on psychosis when it was established in 2009 but subsequently expanded its remit in 2012 to look at all mental disorders for people as young as 14. In its first two years of operation it only supported 10 people with first episode psychosis (Bombonato et al., 2014).

There has been virtually no economic analysis of EI programmes in Italy. A very small scale exploratory economic analysis comparing 23 service users who had been enrolled in Programma 2000 for five years were compared to a matched group of people who had received standard public inpatient and outpatient psychiatric facilities (Cocchi et al., 2011). While the small size of the study means the results must be treated with extreme caution, the exploratory economic evaluation suggested the EI service may be associated with lower health care system costs and greater (albeit non-significant) improvements in clinical outcomes. Importantly the trial also looked at the fidelity of treatment delivery; this was very positive – only 10% of professionals did not

achieve a good level of competence, while more than 50% of all treatment sessions were considered optimal. Dropout rates by participants were also low at less than 10%.

#### 4.6.1 The GETUP PIANO trial

A research grant from the Italian Ministry of Health also funded a major multi-centre cluster randomised control trial (GET UP (Genetics, Endophenotypes, Treatment: Understanding early Psychosis) PIANO (Psychosis: early Intervention and Assessment of Needs and Outcome) involving all community mental health centres in two entire regions (Veneto and Emilia Romagna), and in the cities of Florence, Milan and Bolzano in northern Italy. This total area has a population of 10 million. The aim was to evaluate the effectiveness of embedding components of a first episode psychosis service within community mental health centres rather than in stand alone specialist services. 444 people aged between 18 and 54 either received treatment as usual (pharmaceuticals and clinical management) or an enhanced service which included some of the core elements of an early intervention service: cognitive behavioural therapy sessions, psycho-educational sessions for family members, and case management (Ruggeri et al., 2012, Ruggeri et al., 2015). Services were provided by existing community mental health service staff who had undergone six months of training. At nine-month follow-up those in the intervention groups had significantly better outcomes on the PANSS (Positive and Negative Syndrome Scale) total scale, although there was no significant difference in the number of days of hospitalisation between the two groups (Ruggeri et al., 2015). As Box 9 indicates the authors conclude that it is possible to embed early intervention for psychosis services within mainstream mental health services; this may be an alternative to specialist stand-alone services in some country contexts, although longer term evaluation is still required.

#### Box 9. GETUP PIANO conclusions

Mainstreaming early intervention services within mental health services is a feasible and effective option in some country contexts:

*“A model of generic services adopting the principles of early intervention for first episode psychosis patients complements specialised stand-alone services and is a valid alternative in countries in which stand-alone services experience accessibility problems or cannot be implemented. Our novel findings provide robust empirical support of initial reports that first episode psychosis units can be embedded in generic mental health services.”* (Ruggeri et al., 2015)

## 4.7 NORWAY

Health care in Norway is largely tax funded and significant resources have been invested into mental health services that have been the subject of major reform over the last 15 years. As in Denmark some EI programmes in Norway have been the subject of considerable research, including very long-term follow-up of service users. Early intervention and early detection programmes focused on people aged 15 to 65 have been developing for almost 20 years, with a catalyst being the TIPS (Early Treatment and Intervention in Psychosis) programme, where specialist early detection and awareness programmes targeted at the general public, schools and health care professionals were included in one newly established early intervention programme covering two administrative regions of Rogaland County in Norway (population 370,000) in 1997; these were compared with two new early intervention teams, one in the Ullevål district of Oslo (population 190,000) and another in Roskilde in Denmark (population 285,000) where early detection programmes were not included (Johannessen et al., 2001) (Friis et al., 2005). The inclusion of early detection into the early intervention service in TIPS was associated with a reduction of 1.5 years in the duration of untreated psychosis. The subsequent treatment programme received by individuals experiencing first episode psychosis ran for two years, making use of antipsychotic drugs, psychotherapy and multi-family psychoeducation.

Many papers have been published on the initial circa 300 service users who participated in TIPS between 1997 and 2000, as well as looking impacts on later groups of service users (Larsen et al., 2006, Joa et al., 2008, Melle et al., 2008, Johannessen et al., 2011, Larsen et al., 2011). For instance intensive information campaigns in Rogaland county were halted between 2002 and 2003 the level of early detection decreased, again suggesting that the awareness campaigns had been effective (Joa et al., 2007).

### Box 10. Long-term impacts of TIPS

A 10-year follow-up of study participants has suggested the persistent of benefits including a greater rate of employment than seen in groups receiving standard care (Hegelstad et al., 2012).

Evaluations and epidemiological studies have also highlighted other programmes in Norway; one example of another early intervention service described is that at the Ostmarka psychiatric hospital in Trondheim which serves a population of 255,000 (Møller and Linaker, 2006). Integrated biomedical and psychosocial treatment for first episode psychosis has also been evaluated within a mental health service in Sør-Trøndelag county (where Trondheim is located) (Grawe et al., 2006).

## 4.8 SPAIN

In several of the countries that we examined services remain very limited and many early intervention services (where they exist) have relied on research funding. Spain falls into this category despite the existence of guidelines jointly produced by the national Ministry of Health in Madrid and the Department of Health of the government of the autonomous community of Catalunya which recognise the importance of addressing first episode psychosis, through a combination of different actions, including focus on stigma and protection of physical health (Grupo de trabajo de la Guía de Práctica Clínica sobre la Esquizofrenia y el Trastorno Psicótico Incipiente, 2009).

These guidelines also recognise that more emphasis needed to be placed on prevention of mental health problems in general, something that the current system in Spain where mental health services are provided in specialist mental health centres does not cover well. Limited attention has been placed on training primary care professionals and others (such as teachers) to recognise people who may be at high risk of psychosis (Lluis et al., 2007). Separate Catalanian specific guidance emphasises the importance of having a multi-component approach involving different psychological and family therapies, as well as the importance of having some focus on education and employment interventions (Department de Salut, 2011).

In spite of this recognition at policy level and in clinical guidelines of the importance of both early detection and early intervention for psychosis our review suggests that actual developments in the provision of services have been very limited. Moreover, despite the fact that health economics capacity in Spain is good, we were unable to identify any studies looking at the cost effectiveness of EI services. Furthermore, existing services rely heavily on research funding.

In Cantabria the First Episode Psychosis Programme (PAFIP) at the Marques de Valdecilla hospital in Santander serves a population of 540,000 (Crespo-Facorro et al., 2009); it has received funding from the regional government in addition to research grants. The multi-component service includes both pharmaceutical and family psychoeducational services and treats service users with first episode psychosis ranging from age 15 to age 60 (González-Blanch et al., 2010). Also in Cantabria, a EI team covering the towns of Torrelavega and Reinosa – about 170,000 people – includes early detection as well as treatment (Irurzun et al., 2010); a multidisciplinary first episode psychosis unit at Cruces Hospital in the Basque country has also been operating since 2003.

In Madrid, the PIENSA (Programa de Intervencion en Psicosis Adolescente) programme at the Gregorio Maranon Hospital focuses on early intervention for adolescents. It is however a pilot research study rather than being funded through the health service, and is focused on evaluating the impacts of different types of psychoeducational group interventions on hospitalisation and visits to hospital emergency departments (Calvo et al., 2014) (Ruiz-Sancho et al., 2012). Another multi-

#### Box 11: Sant Pere Clavel early intervention team, Barcelona

Services here are targeted at young people between 14 and 40 years of age who either have been identified as having a high risk for psychosis, as well as those experiencing first episode psychosis, or are in the post-crisis stages of psychosis (Martínez et al., 2011).

The service also provides intensive community support for service users who find it difficult to engage with services, and there are weekly visits with a psychiatrist, psychologist, social worker and/or nursing staff and individual treatment plans are developed. Individuals are followed up for five years.

disciplinary unit for early intervention for psychosis can be found at the 12th of October Hospital in Madrid; again this is very much an exploratory service which has dealt with just 87 service users in its first five years of operation (Belloso-Roper, 2014).

In Catalonia some early intervention programmes have been developed as part of the region's Mental Health Plan. There are many different potential referral points for these services including schools, social services and general practitioners. Treatments include individual and group therapy, psychotherapy, psychoeducation and pharmacotherapy (where necessary). Family therapy is always offered. One example is the development of an EI team at the Sant Pere Clavel hospital which serves part of the city of Barcelona (Box 11).

Elsewhere in Barcelona, in the districts of Les Corts and Sarria-Sant Gervasi, the Programa de Atención Específica a las Personas con Trastornos Psicóticos Incipientes (PAE-TPI) also provides an early detection and early intervention service. This service has a website Espai Jove.net (Youth Space) which is focused on educating young people on how to protect their mental health. It also organises face to face meetings for young people and also parents to raise awareness of potential risk behaviours for psychoses. Another example is the Pedro Mata Institute in Reus and Tarragona. The service also has a pilot early detection and early intervention team serving approximately 150 people aged 15 – 35. The Barcelona team known as Early Care Team for At-Risk of Psychosis Patients covers another catchment area in the city, with a focus on both early detection and providing support for people with first episode psychosis aged from 12 to 56 (Quijada et al., 2010).

## 4.9 IRELAND

Although there has been interest in early intervention services in Ireland, less than 10% of the population have access to an EI service, with only one major service being available – DETECT in the Dublin area. It was estimated that a further nine EI

programmes would be needed in Ireland to cover the needs of the entire country (Omer et al., 2010). The National Clinical Mental Health Programme Plan (2011) did identify early intervention in psychosis as one of three areas for roll out nationally.

Three further services have been developed, COPE covering Cavan and Monaghan, one team in West Dublin and a team in Cork. Budgetary constraints have delayed broader implementation. The planned approach to expansion in Ireland now involves the embedding of EI specialists within community mental health teams rather than the establishment of separate mental health teams. The specialists have to divide their time with other duties for other population groups.

Ireland's first early intervention for psychosis service, DELTA was established in 2005 and based in the Cluain Mhuire area of south east Dublin, covering a catchment area of 175,000 (DETECT, 2011). It was funded by a national charity, the St John of God Hospitaller Services, and subsequently expanded with funding from the public health system – the Health Service Executive – in 2006 to become the Dublin and East Treatment and Early Care Team (DETECT). DETECT now serves a catchment area of 375,000. It provides services for individuals aged 16 to 65 referred for assessment for possible psychotic symptoms (O'Callaghan et al., 2010). In addition to education for a wide range of groups including the police, teachers and health care professionals, the team also provides multi-disciplinary care for those identified as having a first episode of psychosis. Specifically the team provides psychological and occupational therapy as well as support for families. Any need for medications is managed separately by an individual's local mental health service. In its first four years of operation more than 600 people were referred for assessment, 53% of whom were found to have psychosis and 5% to be in a high risk state for psychosis (O'Donoghue et al., 2012). The service has been well received by local primary care professionals (Renwick et al., 2008) and a recent economic analysis suggests that it has been associated with significant decreases in inpatient hospital costs (Box 12).

#### Box 12: Estimating the Cost and Effectiveness of Early Intervention on In-Patient Admission in First Episode Psychosis in Ireland

Experience following the introduction of the DELTA programme was compared to a historical cohort of people with psychosis in the same catchment area. The study found “significant reductions in the duration of untreated psychosis arising from the early intervention programme. Significant reductions in length of stay were accounted for by differences in baseline age and marital status. The average cost of admission declined from €15,821 to €9,398 in the early intervention cohort”. The introduction of the early intervention team appeared to be the main reason for this decrease in costs but the analysis was limited to impacts on inpatient costs (Behan et al., 2015a).

## 4.10 OTHER EUROPEAN UNION EXPERIENCE

Our review confirms the limited availability of EI services in most of Europe, with almost no services identified in the new Member States of the EU. This is not particularly surprising; mental health services receive a low share of health care budgets in most eastern European countries and mental health services in many of these countries remain highly hospital focused with little development of genuine community based mental health services. In this section we briefly highlight some examples of service development elsewhere in Europe.

### 4.10.1 Poland

The first EI centre in Poland was established in Lodz in 2009; this both identifies individuals aged 14–29 in an at risk state for psychosis, as well as providing appropriate pharmacological therapy, CBT and omega-3 fatty acid supplements – they do not provide family interventions or family therapy. Furthermore clients who develop full psychosis are referred on to conventional hospital psychiatry based services (Kotlicka-Antczak et al., 2014).

### 4.10.2 Croatia

An early intervention programme for people aged from adolescence to 50+ and their families was established in 2007 at the Sveti Ivan hospital in Zagreb, Croatia (Restek-Petrović et al., 2012). The multi-disciplinary team provide psychological and psychoeducational interventions, as well as pharmacological care, but do not appear to include support for education or employment.

### 4.10.3 Finland

In Finland early intervention teams are rare due to low population density in most of the country. Intervention teams, when available, are located in major urban centres, including one based at Helsinki central hospital that has been evaluated and shown to be associated with improvements in levels of remission, depression and hopelessness (Granö et al., 2014)

### 4.10.4 Greece

In 2007 the first EI service in Greece was opened, operating within the resources of a newly established mobile mental health unit working in a remote rural in the north west of the country (Mantas and Mavreas, 2012). The service appears to have been restricted to pharmacological and pharmacological interventions with no specific focus on social functioning.

#### 4.10.5 Iceland

In 2010 an early intervention service opened in Reykjavik at Landspítali – The National University Hospital of Iceland (Briem, Olafsson and Friðgerður Víðisdóttir, 2014). The service is targeted at young people aged 18–30, and includes most of the recommended elements of an EI service. An assessment and crisis team meets with all potential service-users. Each service-user has a case manager. Services include psychoeducational programmes, cognitive behavioural therapy, relapse-prevention, family-work, music and art workshops and a recently established vocational rehabilitation programme based on the Individual Placement and Support model. Service-users have free access to a fitness centre and advice from trained sports fitness staff. The service is offered for up to 3–5 years based on individual needs. In April 2014 it was helping 50 men and 12 women.

### 4.11 EXPERIENCE OUTSIDE OF EUROPE

In this section we look at service development in two countries, Australia and Canada.

#### 4.11.1 Australia

Australia has been at the forefront of research on early intervention services for psychosis, but the actual development and availability of services across the country has proceeded in a relatively piecemeal way, albeit with a recent significant injection of funding by the Commonwealth government to increase the availability of specialist services. Leading researchers continue to be key advocates for the development of services and a major review of the country's mental health system has just been published by an independent National Mental Health Commission.

First episode psychosis services evolved out of a research and recovery programme set up in the 1980s at a hospital in Melbourne. It also provided community based services and focused on the initial two years after psychosis diagnosis. These research efforts led to the Early Psychosis Prevention and Intervention Centre (EPPIC) being set up in Melbourne (McGorry et al., 1996) in 1992. Developed by Orygen Youth Health, and receiving public funding from the Victorian state government, EPPIC was initially targeted at young people aged 15–30 in Melbourne.

Key components included mobile detection and assessment teams that aimed to raise awareness about psychosis, a multi-disciplinary team that subsequently supported young people with psychosis in the community, structured group psychological therapies, family therapy, pharmaceuticals and inpatient care 'as a backup and last resort' (McGorry, 2015). EPPIC was followed by the development of first episode psychosis services elsewhere, some embedded within existing mental health services. These, for instance, included the creation in 1997 of specialised early intervention for

**Box 13: The Bondi Centre Early Psychosis Programme, Sydney, New South Wales**

The Bondi Centre, Early Psychosis Programme, is part of the Eastern Suburbs Mental Health Program, South Eastern Sydney Local Health District, which operates from a large house in Sydney's Bondi Junction and treats young people, aged 15 to 25, who have experienced their first episode of psychosis.

Comprised of a multidisciplinary team of psychiatric nurses, psychologist, psychiatrist, family therapist, dietician and occupational therapist, the Programme performs a full mental health assessment on each client and manages the psychiatric, lifestyle and vocational recovery of its clients.

The Programme also conducts a two-year comprehensive multi-disciplinary recovery programme – the RaDiCaL Group Programme (Recovery and Discovery in Community and Lifestyle) to improve general physical health and promote a healthy lifestyle.

Clients of the Programme are also assisted by exercise physiologists and dietitians through the development of a healthy lifestyle plan and individualised exercises through the "Keeping the Body In Mind" programme and use of the onsite gym at the Bondi Centre.

psychosis team at the Noarlunga Hospital in Adelaide in South Australia (Rowston, 2002). This service included similar service components to those initially seen in EPPIC.

Today some services are provided directly by the health care systems in some Australian states, as at the University of Brisbane hospital in Queensland or the Bondi Centre service in Sydney (Box 13), but the availability of dedicated early intervention services has been variable e.g. until recently there was no service at all in the entire state of Tasmania.

The charitable initiative, 'Headspace' – services provided by the National Youth Mental Health Foundation – has recently been critical in the expansion of services in Australia, in terms of obtaining federal government funding for greater service availability. Led by a very visible champion, Headspace has been very effective in engaging with the policy environment at state and federal level securing support from all major political parties.

The 2013 national report card on mental health in Australia noted that *“successive governments at a national and state level are investing more in early intervention approaches for young people. Nationally we are seeing a range of early intervention services: headspace centres and e-headspace, early psychosis intervention services, online supports and games such as ReachOut.com, Bite Back and SPARX, and*

*initiatives targeting schools and universities, such as the Schools Early Action Program in Victoria and Batyr*" (National Mental Health Commission, 2013). In addition to national level policy documents, recent analysis also indicates that discussion of early intervention in psychosis services features in mental health policy documents produced by four states: New South Wales, Victoria, Western Australia and South Australia (Pirkis et al., 2014).

A nationwide programme supporting the roll out of headspace centres (for youth mental health in general) began in 2005; with some of these centres including early intervention for psychosis services. The current coalition government in its 2013 general election campaign also committed themselves to support for mental health for young people (Liberal-National Coalition, 2013). Subsequently the 2014–15 federal budget allocated \$A14.9 million over four years for ten new headspace centres and an evaluation of the programme, and \$A 18.0 million over four years for the establishment of a National Centre for Excellence in Youth Mental Health (Australian government, 2014). 20 headspace centres with early psychosis programmes were to be operating in all Australian states and territories by the end of 2015 (Headspace, 2015). This has included opening of the first early intervention for psychosis services in Tasmania. Total national government funding for all 100+ headspace centres is estimated to be \$A222 million by 2016 (McGorry, 2015). There is also matched funding for centres from the state governments (McGorry, Bates and Birchwood, 2013).

Headspace and EPPIC have also influenced the ethos and scope of services. To reduce stigma and improve accessibility and acceptability of services the focus has moved towards the creation of youth orientated centres on mental health and wellbeing rather than 'psychosis centres' in Australia. The ethos of this service is around collaboration with young people to ensure that support is youth-friendly, delivered in low-stigma community settings and focused on outcomes relevant to young people. Care and support is provided for two years. Services focus on all mental health needs and not just psychosis, but some of the centres include the Headspace Youth Early Psychosis Programme, which makes use of a modified version of the EPPIC service model that over time has evolved to a programme where multi-disciplinary team based services have a strong focus not just on a young person's mental health but also look at their physical health, work and/or educational status and personal relationships with friends and family.

The EPPIC model has included vocationally oriented group programmes and referral to federal government agencies that provide employment support; there is also ongoing evaluation of the use of 'individual placement and support' services for people experiencing first episodes of psychosis where individuals are helped to obtain competitive employment with continuing support for as long as needed (Killackey et al., 2013). Mobile and e-based support services are now also provided and creative group activities offered. Programmes will also have a dedicated service for young people identified as being at ultra-high risk of developing psychosis (McGorry, 2015).

Figure 4. Existing Headspace Youth Early Psychosis Programmes September 2015



Another important development from a policy perspective is greater recognition of the importance of protecting the physical health of all people with psychosis. The National Mental Health Commission has recommended the adoption of the Healthy Active Lives (HeAL) Programme as the standard intervention framework for people with psychosis on antipsychotic medications, to support their physical health and wellbeing, and enable young people experiencing psychosis to have the same life expectancy and expectations of life as their peers who have not experienced psychosis. The policy had previously been adopted within the New South Wales mental health strategy (NSW Mental Health Commission, 2014). Dedicated health coaching, dietetic support, exercise programmes and youth peer wellness coaches, provided as part of a first episode psychosis service in Sydney, have recently been evaluated in a small scale study which reported statistically significant differences in weight gain compared to standard case management services (Curtis et al., 2015).

#### 4.11.2 Canada

Like Australia, specialist early intervention services for psychosis have been developing over more than twenty years, mainly concentrated in the most populous provinces of Alberta, Ontario, British Columbia and Quebec. The Prevention and Early Intervention Programme for Psychoses (PEPP) has been operating in London, Ontario since the 1990s. It has also been extensively researched. Focusing on adults between the ages of 14 and 35 and serving a catchment area of more than 400,000 people it has offered an assertive case management led programme delivered predominantly on an outpatient basis by a multi-disciplinary team including social workers, nurses, 2.5 FTE psychiatrists, an occupational therapist and a clinical psychologist specialising in cognitive-behavioural therapy. Case managers provide care to 12 new cases per year at the London site. Treatment includes assessment and monitoring of symptoms, structured family psychoeducation; group psychosocial interventions to improve social-personal skills and self-efficacy, early use of low dose antipsychotics and cognitive behavioural therapy (Malla et al., 2007).

The programme was replicated in Montreal where one of the programmes founders moved. PEPP Montreal at the McGill University's Douglas Institute started operating in 2003; one of the group activities it runs is a meal preparation and nutrition programme. PEPP Montreal also refers clients to Individual Placement and Support services to help promote participation in employment. Another PEPP services operates at the Institute Universitaire en Sante Mentale de Montreal for Francophone clients. Ongoing research in Montreal includes a randomised trial looking at the benefits of extending the duration of early intervention services from two to five years (Lutgens et al., 2015).

To get a broader overview of services in Canada we can look at the work of the Canadian Consortium for Early Intervention in Psychosis. It undertook a survey in 2013 looking at the services provided by existing 11 academic early intervention programmes in Canada (Nolin et al., 2014).

While there is no national guidance on services, three provinces (British Columbia, Alberta and Ontario) do have guidelines and the survey found that services in those provinces followed most of the provincial recommendations. Generally the 11 programmes all offered case management led multidisciplinary teams and various psychosocial interventions, including individual cognitive behavioural therapy. All provided pharmacotherapy and family therapy, while eight of 11 provided employment support and six support with education. Nine of the 11 programmes provide physical activity/sports programmes. However, there are differences in admission and discharge criteria with four programmes excluding substance induced and three affective psychosis. While all support people up to age 30 or 35, three did not accept people below age 18. 70% run for between 2 and 3 years, caseloads range from 8:1 to 50:1 in programmes, and only three programmes offered services for people at ultra-high risk (UHR) for psychosis.

# 5 CHALLENGES AND OPPORTUNITIES

This section summarises the challenges and opportunities faced by different European countries in developing early intervention services. Many of these challenges and opportunities are common across several countries, including those outside of Europe.

## 5.1 LIMITED AVAILABILITY OF SERVICES ACROSS EUROPE

Despite the body of evidence on the effectiveness of EI services and promising evidence on their cost effectiveness, the key challenge remains the lack of mainstream secure funding in Europe. Figure 5 provides an overview of the state of specialist EI services in Europe. Countries shaded in green have significant networks of EI services nationwide; the four countries of the UK lead the way with the most extensive network of services within the publicly funded national health service; networks of funded services are also to be found in Denmark, Norway and Switzerland. Iceland has just one early intervention service at the National University Hospital, but this appears to provide substantial coverage for all of the country. Even in these countries available services are unlikely to be sufficient to meet predicted potential demands. In Denmark it continues to be argued that there is insufficient coverage to meet population need.

A second group of countries shaded in yellow have a more limited network of EI services often situated in just a few locations in a country, as in Ireland or support very small numbers of service users as in Italy. Services may often be seen as research activities rather than mainstream services, as in Germany and Spain. In Spain, where responsibility for health care is devolved to the regions, EI services were only found in four of the country's 17 autonomous communities. In Italy, EI services have been concentrated mainly in the northern and central regions of the country.

The third largest group of countries, shaded in red, have few, if any specialist, EI services, nor have there been any significant policy developments which might suggest that services might expand in future. This group of countries includes France, where not only are there almost no EI teams, but one key element of any EI service, psychological therapy services, are not normally reimbursed by the publicly-funded health system.

Figure 5: Overview of the development of specialist EI services in Europe



Figure 6: Countries identified undertaking research on EI services



Countries left unshaded in both figures are those where no information could be obtained

Figure 6 does however indicate a broader group of countries, including some in eastern Europe, where evaluations and other research on EI services have been conducted.

## 5.2 TIME-LIMITED FUNDING AND FINANCIAL CONSTRAINTS ON HEALTH SYSTEMS

We have highlighted that in many European countries some EI services have to rely on research and other short term sources of funding due to a lack of mainstream health system funding; this affects the provision of services in Denmark, Germany and Spain. The system in Germany is characterised fragmented funding and disincentives to fund multi-disciplinary care for psychiatric services. There have been few financial incentives to develop EI programmes as routine service options; instead they are restricted to activities of research networks in a number of large cities.

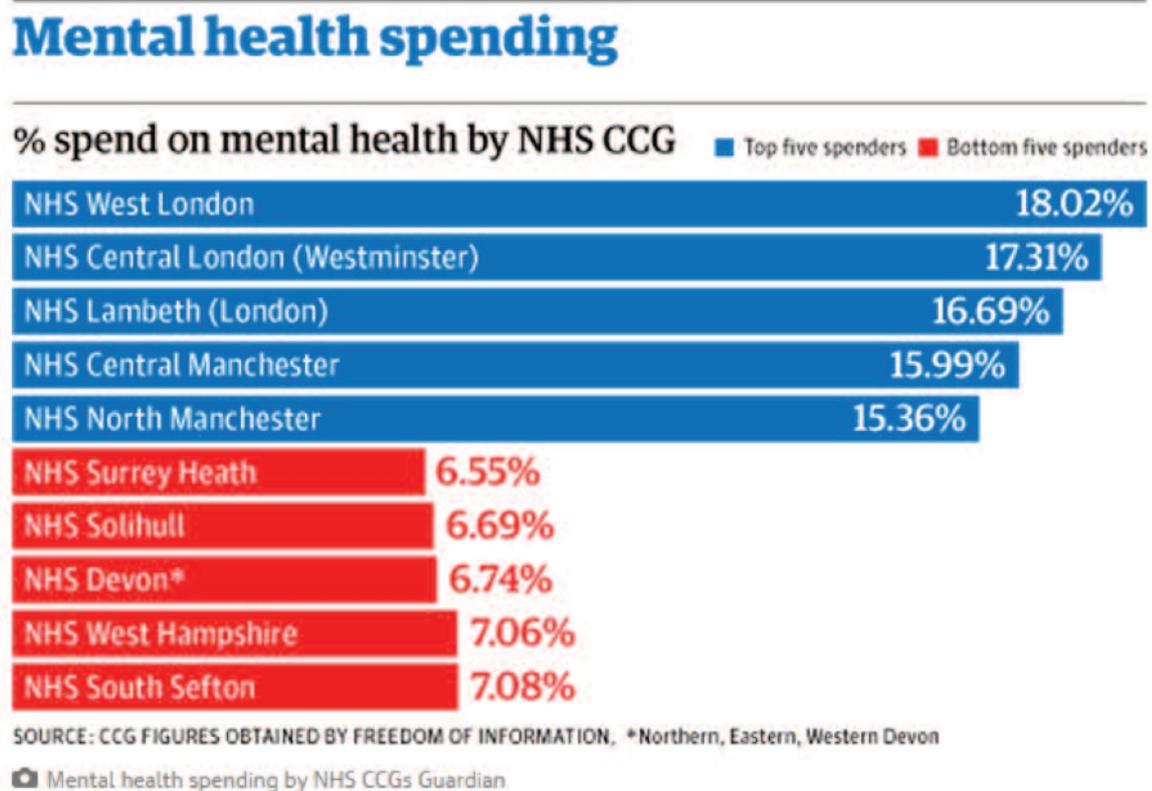
Even where the availability of services is good, the current economic climate is placing substantial strains on services. In England overall spending on adult mental health services has declined in real terms since 2011 after a decade of growth (Mental Health Strategies, 2012, Campbell, 2014, McNicoll, 2014a). The tight NHS spending environment, where local budget holders (clinical commissioning groups) were given the challenge of saving £20 billion during the lifetime of the last Parliament, with further spending cuts to come, may have made funding for mental health services (traditionally viewed as less important because they are erroneously not seen as life threatening) more vulnerable to cuts than services for physical health problems.

## 5.3 LACK OF PROTECTION FOR EI BUDGETS

If funding for EI services is not protected then it may be diverted to other activities. In France the financing system does not safeguard funds for mental health; budgets allocated to mental health in a catchment area can in fact be used by hospitals for different purposes; psychiatric units are often co-terminus to parent somatic hospitals.

This can also be seen in England. Funds are distributed from a national body NHS England to local Clinical Commissioning Groups who are then responsible for commissioning the majority of health services in their local areas, often entering into a contract with one mental health trust for the provision of services. However, while the allocation of resources notionally has included an adjustment for local mental health needs, funds are not earmarked and CCGs and their predecessors (Primary Care Trusts) have always had discretion on how much funding they actually devote to mental health services (McDaid, 2011b). This has led to considerable variation in spending. As Figure 7 indicates some CCGs are spending less than 7% of their budgets on mental health compared with more than 18% in others. While some variation will be inevitable, this analysis found that in areas with equal need and similar socio-demographic characteristics spending in one may be less than half that of the other (Campbell, 2014).

Figure 7: Variation in mental health spending by CCG in 2014



Source: *The Guardian* (Campbell, 2014)

## 5.4 LACK OF GUIDELINES AND POLICY DOCUMENTS

Policy documentation and accepted guidelines on care pathways can help facilitate the development and general acceptance of EI services, as well as promote fidelity in the way in which they are delivered. Why policy documentation and guidelines can be found in the Nordic countries, the UK, Ireland, Italy and Spain, early intervention services do not appear to be mentioned in policy documentation in France. In the case of Italy local studies have noted a need to ensure better training and support is provided for existing and new EI services so as to improve their ability to adhere to national guidelines and better identify and support people with psychosis.

Guidance alone, however, is unlikely to facilitate service development. In England guidance has indicated that urgent referrals to early intervention services should be

seen within three days and non-urgent cases within 7 to 14 days. Local areas had discretion to set targets related to psychosis with service providers and funders if they so wished as part of initiatives to improve productivity and service performance. In some cases a share of funding (up to 2% of a contract can be linked to achievement of targets, but incentives related to services for people with psychosis have not featured heavily. For instance, the Worcestershire Health System Delivery Plan 2011/12 – 2014/15 had a focus on the WHSCT reducing DUP through better compliance with EI best practice. This was measured using the number of new EI patients who have a DUP of under three months, size of EI caseload and rates of readmission rates (Worcestershire Joint Commissioning Unit, 2011). Until recently there had been no national waiting time targets to incentivise local service funders and providers to meet targets. New national waiting time targets to incentivise local service funders and providers to meet waiting time targets will be introduced in April 2016. Failure to achieve targets will lead to a loss of funding.

## 5.5 MENTAL HEALTH SYSTEM STRUCTURE AND LINKS WITH PRIMARY CARE

Some mental health systems continue to have a heavy reliance on hospital oriented services; this can act as a barrier to the development of mobile EI teams capable of operating in multiple venues in the community. This is evident in France where community, rather than hospital, oriented mental health services are rare. It is also a reason for the very limited development of community mental health services in eastern Europe. Hospitals may be paid for bed occupancy rates; again discouraging the development of mobile services. This has also been an issue in Germany, but new legal structures that allow for the provision of integrated care for mental health services could make it easier to develop EI services. In Italy, one challenge is to promote better coordination and collaboration with different agencies to promote continuity of care.

A related issue concerns the links with the primary care systems in countries. Duration of untreated illness may be due partly to poor level of contact with the primary care system; again in France people at risk or experiencing a first episode of psychosis may not be registered with a gatekeeping primary care doctor (medecin traitant). The median duration of untreated psychosis for people experiencing a first episode of psychosis was estimated in one small study in Bordeaux to be 28 weeks, although in this sample more than 60% of clients were compulsorily admitted (Cougnaud et al., 2006). This suggests that people with less developed symptoms of psychosis may not be coming into early contact with services.

## 5.6 LIMITED PROVISION OF SERVICES FOR OLDER PEOPLE EXPERIENCING FIRST EPISODE PSYCHOSIS

The issue of late age of onset (over the age of 40) of psychosis has been less well studied than early onset psychosis, but about 25% of all new cases of schizophrenia emerge after the age of 40 (Harris and Jeste, 1988, Howard et al., 2000). Recent Australian research looking at first episode cases attending one hospital found that while there was an initial peak in presentation to first episode psychosis programmes between the ages of 17 and 22 there is also a second peak between 45 and 50 accounting for 22% of all cases (Selvendra et al., 2014).

Despite the fact that more than one in five of all cases of first episode psychosis are seen in people over the age of 40, most of the EI services we identified are targeted at people under the age of 40, as is the case in England where early intervention services in England are targeted at people no older than 35. This may potentially mean that some people with first episode psychosis never have an opportunity to be identified early and treated with specialist EI services. It also suggests that services and supports in EI programmes may need to be adjusted to meet the needs of older people.

## 5.7 FURTHER EVALUATION

Another challenge is the need to strengthen the evidence base, particularly on cost effectiveness, in many European countries. This can help strengthen the argument for investment but we were unable to identify any assessment of cost effectiveness of EI service models in Germany, Spain or France, with only very limited preliminary assessment in Italy. In Italy it was also noted that there is also a need to embed routine data collection and performance evaluation into EI services. More generally in Europe there is a need for longer term effectiveness and economic evaluation covering a wider range of impacts, including physical health and participation in education.

## 6 FACILITATORS FOR SERVICE DEVELOPMENT

Our review of EI services in Europe certainly indicates that services have expanded over the last 15 years, but in many respects the glass can be characterised as being half empty rather than half full. In this section we set out some recommendations related to potential facilitators for the development of EI services in Europe. Box 14 sets out our main recommendations on actions that may help facilitate the development and implementation of EI services more widely in Europe.

### Box 14: Actions to help facilitate the development and implementation of EI services

- Pilot evaluation of different models of EI services fully embedded within publicly funded health systems.
- Strengthen and make use of evidence on the effectiveness and cost effectiveness of early intervention, including examining impacts on physical health and impacts beyond the health sector.
- Identify champions who can help raise awareness of evidence on the effectiveness and cost effective of EI services.
- Promote fairer funding of mental health services.
- Look at ways to modify payment mechanisms to encourage development of EI services.
- Support collaboration with primary care services.
- Reform institutional structures to widen access to EI services
- Broaden the focus of EI services to address social functioning
- Monitor implementation and fidelity in service delivery
- Improve access to information on the availability of services

## 6.1 PILOTING AND EVALUATING DIFFERENT MODELS OF EMBEDDED SERVICES

With very few exceptions, England (and the UK more generally), Denmark, Norway and to some extent Italy, EI services are not well embedded within publicly funded health care systems. Services are also available in Switzerland where the level of private funding is greater than in other European countries. EI services are funded by the Irish public health system, but are only available in parts of Dublin and two other locations in the country; the challenge of providing services elsewhere is still to be addressed. Elsewhere EI services are often relying heavily on research funding, as in Spain, or have a limited but strong research focus as in Germany. There is much uncertainty about their sustainability, let alone potential for expansion. Despite significant funding for mental health in France, the concept of EI has not been embraced and very few examples of services are to be found. We also only identified pilot EI services in two hospitals in the post 2004 EU Member States, one in Poland and one in Croatia. An early intervention service for people with psychosis was established with funding from a British non governmental organisation in Tallinn, Estonia more than 10 years ago, but this service is no longer in operation.

Outside of Europe, services are to be found in Australia, Canada New Zealand, Hong Kong, Japan, Singapore, South Korea and the USA. Few services exist in low income countries, which may have more pressing concerns in simply rolling out the most basic of mental health systems. Some services can be seen in middle income countries, but again these are few and far between – one mapping exercise looking at all of Latin America found only seven services, six in Brazil and one in Mexico (Brietzke et al., 2011).

Evaluating the impact of embedding early intervention services within existing mental health services may help to demonstrate that early intervention service models can be adapted to operate in contexts and countries where implementation has been limited. This is particularly the case in parts of Europe where services are very limited; piloting services makes sense; service models may need to be adapted to function in different country contexts to where they have been evaluated. Pilot studies can also be used to evaluate different approaches to the expansion of early intervention services, including a greater focus on social functioning outcomes such as educational achievement and employment.

Studies such as the recent large scale GET UP PIANO feasibility trial in Italy have also looked at training general mental health staff to provide EI services. This study concluded that it was possible to task shift early intervention service activities to the existing staff and infrastructure of the community mental health centres that are found throughout the country (Ruggeri et al., 2015). More generally, evaluation and monitoring

need to become a routine part of the culture of service delivery, something that may be challenging to achieve in all country contexts (Cocchi et al., 2015). Embedding EI services within community mental health teams will also be used in Ireland to expand access to services.

## 6.2 STRENGTHENING AND MAKING USE OF EVIDENCE ON EFFECTIVENESS AND COST EFFECTIVENESS OF SERVICES

Policy makers and health service budget holders are unlikely to be convinced of the merits of investing in specialist EI services without credible (and ideally context relevant) evidence on their effectiveness and cost effectiveness. There may be scepticism about the effectiveness of services to overcome; and there will always be many alternative ways of using scarce resources. The case for investment in EI services may though be strengthened by routinely making more systematic use of follow-up data on clients of EI services over several years to look at long-term impacts.

The extent to which this can be done will depend on the availability of good information systems which allow the future use of health, social care and other services to be monitored. In Denmark, for instance, data systems even make it possible to track future contacts with the criminal justice system by people who make use of EI services (Stevens et al., 2013). Similar data systems and means for data linkage are to be found in a number of other European countries, most notably in the other Nordic countries. In many respects the leading country in data linkage is Estonia; making it easier to evaluate any services that were to be implemented in this country.

Policy makers will also be interested in the economic case for investing in EI services. So far economic analysis of EI services in Europe has been focused largely in the UK with some limited analysis in countries such as Denmark, Ireland and Italy. There has also been important analysis of the cost effectiveness of specific components of early intervention for psychosis services, notably recently studies highlighting the cost effectiveness of psychological therapies in the Netherlands (Ising et al., 2015). The limited number of economic studies is not unique to Europe, with the exception of Australia and Hong Kong few economic evaluations have been published in other parts of the world, for instance it has been noted that there is a dearth of evidence on whether EI services can be cost effective in Japan (Koike et al., 2011).

Economic arguments on EI services may influence clinical guidelines, as in the case of national guidance in England on schizophrenia (National Institute for Health and Care Excellence, 2014) and in the development of mental health policy in Scotland (Scottish Government, 2012). Both of these documents recommend EI teams and cite economic arguments. Information on the long-term clinical and economic outcomes of

programmes can be very powerful. Ten-year follow-up of adults who made use of the two-year version of the OPUS programme in Denmark did not identify many significant differences in many very long-term health and social care outcomes, but there was a lower use of some specialist housing support services (Secher et al., 2014). Experience in Norway also indicates better functioning in employment at ten year follow-up (Hegelstad et al., 2012), while analysis in Australia illustrates the benefits of helping young people with first episodes of psychosis to complete their education (Smith, 2014). All of these impacts have economic consequences and can strengthen the case for action.

Many EI services only run for two years but there is an emerging evidence base on further improved health outcomes for individuals who continue to receive EI services for longer than 2 years (Norman et al., 2011). Guidelines in England on first episode psychosis now recommend that the NHS should consider extending the availability of early intervention in psychosis services beyond three years if the person has not made a stable recovery from psychosis or schizophrenia (National Institute for Health and Care Excellence, 2014). There are also ongoing evaluations of longer term (five year) intervention programmes, for instance for the OPUS-II programme in Denmark (Melau et al., 2011) and for EI services in Quebec, Canada, (Lutgens et al., 2015) which include health care resource use and other economic analysis. It may be the case that the economic case for investment in EI will be stronger if the duration of intervention is increased.

It is also worth noting that the economic case for the early detection element of services can be strengthened if the impacts on those who are assessed negatively for first episode psychosis are considered. In some cases they may be identified as having other mental health needs, for instance linked to diagnosable levels of depression or anxiety disorders. Early referral to appropriate services to manage these conditions may generate additional benefits, particularly given that only around a third of people with affective disorders come into contact with health services.

### 6.2.1 Impacts on physical health

Another area where the evidence base could be extended is to look at the impacts on physical health of EI programmes. There are likely to be substantial economic benefits from reducing avoidable co-morbidities between mental and physical health problems (Park et al., 2013, McDaid and Park, 2015) but the effectiveness evidence base on achieving these benefits remains very limited (Behan et al., 2015b, Rosenbaum et al., 2015, Hjorth et al., 2014, Speyer et al., 2015). We have highlighted promising work in Australia evaluating a lifestyle and life skills intervention, delivered within 4 weeks of antipsychotic medication initiation (Curtis et al., 2015). Another welcome example of development is the ongoing evaluation in a controlled trial of CHANGE in Denmark – a lifestyle programme focusing on dietary habits, exercise and smoking cessation for people with psychosis. So it is quite plausible to suggest that EI services are being

conservative in estimating their full economic impact if they do not take account of impacts on physical health (and indeed on other co-morbidities such as substance-abuse).

### 6.2.2 Impacts beyond the health sector

It is also important to look at impacts on social functioning, including participation in education and employment, as the majority of the costs of living with psychosis do not fall on health systems but on other sectors of the economy. Some economic analyses have used modelling techniques point to economic benefits beyond the health sector (Park, McCrone and Knapp, 2014). These modelling techniques can be used to synthesise existing data on the effectiveness of interventions with local system specific data on costs and cost effectiveness to help inform policy making. Such approaches can be particularly valuable in the absence of previous local empirical data on cost effectiveness as well as to extrapolate longer term costs and benefits beyond those seen in clinical trials (McDaid, 2014).

If the economic evidence base is strengthened to look at these wider impacts it then becomes imperative to make the case not only to health care system budget holders such as ministries of health and social insurance funds, but also with departments responsible for other public sector spending, including education, housing, social welfare and criminal justice.

## 6.3 ADVOCACY AND CHAMPIONS FOR EI

There are many different factors that can go some way to explaining the very different experiences seen across Europe. The availability of evidence on what works and at what cost is one reason. Another may be the way in which this evidence is communicated to key stakeholders. Effective advocacy and the presence of champions for EI, whether these are leading academics and clinicians or institutional structures such as professional associations and non-governmental organisations, can make a difference. This is most clear from the approach taken in Australia to build a coalition for greater investment in EI (McGorry and Yung, 2003). Champions have also played a key role in England, Denmark, Ireland, Norway and Italy.

Advocacy and engagement with policymakers and other key actors is no trivial enterprise. It requires a lot of time and a recognition that this will imply cultivating relationships and entering into ongoing multi-way dialogue over many years. It is also about strengthening the capacity with the EI community to have the knowledge exchange skills to engage with policy makers. This process can be helped enormously by strong non-governmental organisations – we have highlighted the key role that well-organised mental health charities in England have played in putting early intervention on to the agenda.

## 6.4 PROMOTE FAIRER FINANCING FOR MENTAL HEALTH SERVICES

A challenge in some countries clearly will be capacity, both financial and in terms of skills and expertise, to scale up access to EI services. While this review identified very little psychosis specific data on financing, spending on mental health services in general as a percentage of total health care spending continues to be far below the contribution of poor mental health to the overall global burden of disease. Specialist complex services such as EI are among the more costly services; this may limit the scope for their use to high income country contexts. They may be difficult to justify in some middle income countries in the east of Europe where mental health services in general are in need of major modernisation.

Unfavourable attitudes towards investing resources in mental health services can stymie the development of special mental health services, including EI teams. The general public in some countries may not see mental health as a major priority for health system spending; moreover they may be positively antagonistic to the notion of spending money on services that they perceive would mean that more people with serious mental disorders would be treated in the community rather than in secure remote institutions.

Health budget holders may also not see mental health as a priority, perhaps failing to recognise that it also is a major risk for premature mortality due to physical health problems. Mental health budgets were cut deeply in some European countries, e.g. in Ireland by one-third, during the recent economic crisis (Quaglio et al., 2013). We noted that even in England, where EI services are well established, the overall mental health budget has fallen since 2012 and the budgets of up to 50% of EI services have fallen, putting services under great strain (Rethink Mental Illness, 2014).

Addressing these negative attitudes and misconceptions about the importance of mental health needs to be one element of any mental health strategy. This is linked to our previous discussion of the value of champions to communicate messages and the importance of evidence-based arguments looking at impacts within and beyond health services. In some circumstances it may be prudent to protect and ring-fence mental health budgets in order to ensure that a minimum level of funding is allocated to this area. There are examples of protected budgets for specific types of mental health interventions, such as the Individual Access to Psychological Therapies (IAPT) programme in England, and youth mental health centres, including early intervention in psychosis services, in Australia.

A related issue concerns the way in which mental health services are funded; the most well established first episode psychosis services tend to be in countries which rely predominantly on tax rather than social insurance funds. Tax systems tend not to define a fixed list of services that are reimbursable, in contrast to social health

insurance systems. This greater flexibility on how to use health care funds creates more space for innovative thinking around mental health services.

In a number of European countries that we looked at which rely significantly on different types of social health insurance EI services are underdeveloped. They may not always be seen within categories of services routinely covered by social health insurance, as for instance has been the case in Germany (although potentially this can now change) and in another social health insurance funded system outside Europe – Japan (Mizuno et al., 2012). Also outside Europe, relatively recent reforms to the health system in the United States, ensuring parity in the treatment of mental and physical health issues by insurance companies, may open up greater opportunities for the development of early intervention services, but it is still the case that most services have been funded through research initiatives (De Maio et al., 2015).

## 6.5 LOOK AT WAYS TO MODIFY PAYMENT MECHANISMS TO ENCOURAGE DEVELOPMENT OF SERVICES

It is not just about the ways in which money is collected to fund health services. The way in which services are paid can either stimulate or stifle innovation. In many European countries these budgets are still determined by occupancy rates of inpatient hospital beds; service providers may have very little incentive to change the way in which they allocate resources to provide more outpatient and community-based services if their funding is heavily determined by maintenance of the status quo in the mix of services provided (Knapp et al., 2007).

Having guaranteed activity-based funding streams for EI services through set prices or fees being charged to funders for services delivered, for instance related to Diagnosis Related Groups for mental health remains rare, and accurately calculating these tariffs has been problematic (McDaid, 2011a). Specialist mental health services still tend to be funded through global budgets. Where global budgets for mental health are notionally provided for a specific service provider or health system budget holder in a defined geographical catchment area it does not always follow that all of this budget will in fact be spent on mental health services. In England, for example, the Clinical Commissioning Groups that are responsible for buying most mental health services may choose to spend more or less than the global budget envelope for mental health services that they receive from NHS England. As our review has indicated there are very few examples of mobile EI service teams in France; one obstacle to their development is the discretion that service providers, such as hospitals, have to reallocate some of the budget earmarked for mental health services to other activities that they provide. Payment mechanisms might also be a barrier to integrated physical health care for people with first episode psychosis. Payment mechanisms though can be adapted to include funding for co-morbidities e.g. providing payments to monitor

and manage physical health problems and/or coordinate physical health care with physical health services.

## 6.6 SUPPORT FOR COLLABORATION WITH PRIMARY CARE

Another key issue is the role of primary care. Primary care systems can play an important role in helping people at risk to come into contact with specialist health care services but these fears and concerns need to be addressed. Primary care services can also have an important role to play in ensuring continuity of care after individuals are discharged from EI services.

The most developed EI services in Europe tend to be found in countries with strong primary care systems. Experience in England also suggests that primary care doctors can be better linked with EI services so as to help manage physical health to help prevent and/or reduce the risk of physical health problems and their complications (Lester et al., 2012). In Germany (and Austria) a large number of mental health professionals are in stand alone private practice and are often a first point of contact on the pathway to services, suggesting that primary care practitioners may be of lesser importance (Fuchs and Steinert, 2004). This may though act as a disincentive to more collaborative care models involving primary care practitioners.

Poor links with primary care, and poor knowledge within primary care of mental health services have also been highlighted as one challenge in France (Gozlan, Acef and Petitqueux-Glaser, 2009). But there can also be also fears among primary care professionals that their workloads will be increased unduly if they are providing support to people experiencing first episode psychosis. This implies that EI services could provide better training and support for primary care practitioners. Primary care practitioners can also be embedded into early intervention teams.

## 6.7 REFORMING INSTITUTIONAL STRUCTURES TO WIDEN ACCESS TO SERVICES

Early intervention services in Europe are mostly structured towards people aged between 15 and 35, although access criteria vary between programmes; but about 25% of all new cases of schizophrenia emerge after the age of 40. European EI services might want to explore whether they could extend their age criteria to older people. Careful evaluation is required to see if reaching this wider population might increase their cost effectiveness. How might services have to be adapted and what impact might this have on the use of services by older people? Examples of EI services that cater for older can be seen in some countries, e.g. in parts of Canada.

There may also be structural barriers to people below the age of 18 coming into contact with EI services in some countries, especially where child and adolescent mental health services may be organised and funded separately from adult mental health services. In Denmark, the OPUS programme was not delivered to people below the age of 18, so potentially a proportion of those at high risk of psychosis may not have the same opportunity to benefit from early intervention services (Nordentoft et al., 2015).

Another way in which access may be widened is through changing structures so that contact with services is less stigmatising. Ways of encouraging collaboration and partnership working can include co-location of staff in the same premises or joint training events; experience in England also suggests that having a strong focus on youth-oriented EI services can help overcome institutional barriers and ensure that all relevant age-appropriate services can be hosted in the same venue (England, Lester and Birchwood, 2009). The focus on providing youth orientated centres on mental health and wellbeing rather than 'psychosis centres' has been a key strategy in Australia. This means collaborating with young people to ensure that support is youth-friendly, delivered in low-stigma community settings and focused on outcomes relevant to them.

More evaluation is also required of task-shifting strategies, such as those recently evaluated in Italy, which seek to train general mental health staff to provide specialist early intervention services (Ruggeri et al., 2015). These may be particularly appropriate in resource-constrained settings in some parts of Europe where investment in separate specialist EI services may not be viable. This may also be the case in low and middle income countries where there is growing interest in early intervention for psychosis.

## 6.8 INNOVATION IN PLANNING AND SERVICE DELIVERY

Observed caseloads for EI services have often been higher than that envisaged by governments, suggesting that the epidemiological estimates were too conservative (Cheng et al., 2011). Service planners need more sophisticated methods for estimating the likely incidence rates of psychosis in different localities. One innovative approach has been to build predictive modelling tools, with one example being [psymatic.com](http://psymatic.com) which has been developed for use in England (Kirkbride et al., 2013).

## 6.9 BROADEN THE FOCUS OF EI SERVICES TO ADDRESS SOCIAL FUNCTIONING

EI services where available will usually provide a combination of psychosocial and pharmacological therapies. They are less likely to provide services to support social functioning. In general the focus on social functioning issues, e.g. around education,

employment and housing is much less well addressed than the more clinical elements of service provision. Guidelines on EI services recommend the provision of education, employment, physical health and housing specialists, among others. There are examples of services which include team members with specialist skills in employment, but very few obvious examples of educational support, despite its critical importance to life chances. The importance of managing physical health is also better recognised with some teams employing physiotherapists and sports trainers, but again this is also much less visible.

## 6.10 IMPLEMENTATION AND FIDELITY ASSESSMENTS

EI services, because of their assertive nature, with high levels of contact with service users, should in theory be more effective in maintaining contact with treatment programmes compared to less intense methods. However EI services may not have their intended impact if they are poorly implemented. It is important to understand the environment in which services are to be delivered; this can be aided by understanding not only skills within mental health services but also the attitudes of staff towards EI programmes (Dark et al., 2015). Plans can then be made to address any barriers to implementation that are identified.

Steps can also be taken to improve the fidelity of programmes with evidence-based guidelines on the key therapies and services that they should offer. Fidelity checklists have been developed (Addington et al., 2013); monitoring processes conducted by independent bodies that can make use of appropriate fidelity checks, perhaps through random assessments of services may help to increase fidelity with the EI service model. Service users and families can also play a role in monitoring the fidelity of service provision; fines and /or other penalties for not adhering to the accepted principles of EI might also be levied.

## 6.11 ACCESS TO INFORMATION ON AVAILABILITY OF SERVICES

A final issue, but by no means less important issue, concerns improving awareness, both of the risk factors and signs for first episode psychosis in the community and the benefits of reducing DUP. The duration of untreated illness (which is a combination of duration of initial help seeking delay after the onset of symptoms and treatment delay following a help seeking contact), even in parts of Europe where early intervention services are available, can remain very high, greatly increasing the risks of profound adverse impacts on people who experience in psychosis. In the EPOS study looking at services in England, Germany and the Netherlands in the mid 2000s, analysis indicated that the mean duration of untreated illness was 183.9 weeks – well in excess of 3 years

(von Reventlow et al., 2014). This particular analysis found substantive differences between the three countries, with the community oriented early intervention teams operating in Birmingham and Manchester in England seeing the shortest durations of untreated illness – 117 weeks compared to the more privately provided, hospital oriented systems – 181 weeks in Amsterdam in the Netherlands and 217 weeks in Cologne and Berlin in Germany. In Turku, Finland, where no specialist early intervention was available the delay was 198 weeks. The authors emphasised the important of public awareness campaigns to increase the number of contacts and referrals from non-medical services and the need to expand access to specialist early intervention services, taking into account differences in health care system structures.

In Ireland, analysis of individuals served by an early detection and intervention programme in part of the Dublin area reported a mean DUP of 82 weeks – well over 18 months (O'Callaghan et al., 2010). A further more recent analysis of 14 new and established EI services in England reported much lower median DUP of less than three months: 89 and 77 days respectively (Marshall et al., 2014). More than 60% of all service users had a DUP of less than 60% with new services quickly catching up with their established counterparts. The authors of this study hypothesised that the reduction in DUP was probably due to the catalytic effect on mental health organisations of introducing EI services, 'leading to a more prompt response to first episode psychosis across the whole secondary system of care'. They also noted that there were no significant public awareness or outreach campaigns to detect people with psychosis; the potential additional benefits of the introduction of such campaigns needs to be evaluated.

Many different groups such as staff in schools, workplaces, universities, plus social workers and health and social care professionals, as well as the general public, may be in a position to signpost individuals towards early detection and early intervention services. It is important to have good e-resources identifying services that are available and explaining these in a way that is easy to understand and not written in clinical language. In undertaking this review it has been difficult to identify such a comprehensive list of services provided both for early detection and early intervention and some of the links that were provided on various websites do not function.

There may also be opportunities to use digital technologies to strengthen mental health literacy, as for instance seen in recent work in Ireland where information on the website [www.detect.ie](http://www.detect.ie) targeted at people with first episode/early psychosis, carers and general practitioners was developed into a digital application by a mental health service user, apps developer . Subsequently much higher rates of downloads of this information have been seen using the mobile phone app rather than through the website (Madigan, Kehoe and Clarke, 2014).

## 7 CONCLUSIONS

So what can we say about the state of EI services from this review? Is the glass half full or half empty? It is clear that the evidence base on the effectiveness and cost effectiveness of specialist early intervention programmes for psychosis continues to grow and the benefits of reducing the duration of untreated psychosis are well documented. We can point to well established networks of early intervention services in a few European countries, and the potential to scale up and mainstream research-focused programmes in several other countries. Where early intervention services are well established, they are becoming more complex, offering a wider range of services, including some more focus on physical health, vocational, educational and family support.

The review has suggested ten actions that may help facilitate the further development of services and also justify continued investment in existing services. Some of these actions are about strengthening the knowledge base, for instance increasing what we know about the effectiveness of EI programmes that run for more than two years, or the benefits of programmes to physical health. It is also important to communicate messages on the evidence base in an effective manner; economic evidence, including assessment of benefits beyond the health sector has been helpful in the development of existing EI services in Europe.

The ways in which EI services can be developed also depend on health system structures, including links with primary care. Changes to the way in which services are paid for might be used to help promote continuity of care and collaboration with primary and physical health care services. This is particularly the case in countries where the primary care gatekeeping function is weak and services are funded through social insurance rather than tax funded mechanisms.

There is also a greater need to focus on implementation. Here there is scope for governments and other service funders to monitor the way in which services function, including assessment of their fidelity in delivering services in line with accepted guidelines. This does not mean having to constantly assess all services or set up new structures; a starting point can be to look at existing quality assurance mechanisms for mental health services and see whether they can perform this function.

It is also important to recognise that different health care systems may require different approaches to the delivery of EI services. The existing mental health infrastructure in many eastern European countries, coupled with the budgetary requirements of specialist mental health services, make it difficult to implement EI services. In lower resource settings, can EI models be adapted so that they can be implemented by

different sets of mental health professionals and to what extent could primary care professionals also deliver some aspects of services? These are all questions that require careful evaluation.

Most of the actions will have to be considered in their own country specific contexts, but there is also a role for the EU to play. Firstly it could help to encourage the strengthening of data surveillance systems so that it is easier to make comparisons across countries. This lack of good measures to compare mental health systems has been highlighted many times, most recently by the OECD in their review of selected mental health systems (OECD, 2014). The EU could also play a pivotal role through its Horizon 2020 research programme in helping to strengthen the evidence base on EI services, particularly in country contexts where little is known about these services. Finally, it might also consider whether various infrastructure funding mechanisms could be used to help support the initial development of services in some countries, but this would have to be within the context of fully assessing the key needs of these mental health systems.

So on balance, the glass can be thought of as at least half full in some settings, with increasing capacity, knowledge and interest in EI services, but in others progress has been slow. Ultimately given the profound impacts of psychosis, and the benefits of early intervention, all stakeholders need to work creatively, within their own resource constraints, to improve outcomes for all.

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