



# **EARLY INTERVENTION IN PSYCHOSIS**

**A strategy to develop the Wakefield and Pontefract  
Service by 2004 in line with the 'National Plan' and  
Policy Implementation Guide.**

## **Fellowship Report**

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## **1.0 Executive summary**

There is a growing interest around the world in intervening early in the hope of preventing serious mental illness such as schizophrenia developing. Researchers and clinicians treating people with schizophrenia and psychosis believe that the earlier the condition is detected, the better the prognosis for the patient. Research in the United Kingdom over the last few years has shown that the early years of psychosis is a 'critical period' influencing the long term trajectory of psychosis and the delays in first treatment increase early relapse (Macmillan et al 1986; Birchwood et al 2000).

In treating and managing schizophrenia and related psychotic disorders, clinicians often focus on controlling psychotic symptoms, overlooking outcomes that are more directly related to quality of life and that may be more important to the individual patient and their families (Awad 1992; Corrigan & Buican 1995).

The National Mental Health Strategy (Modernising Mental Health Services, DoH 1999) recognises the central importance of this new approach as do The National Health Service Plan and National Service Framework for mental health which identifies the development of local Early Intervention Services for all members of the population who are assessed as needing such a service as one of its key deliverables. The Department of Health requires that all National Health Service trusts provide early intervention services for clients with early psychosis by 2004.

Wakefield and District Mental Health Services has already shown its commitment by supporting this Health Action Zone project which will set up an audit of pathways of care, mapping out the current service provision and establishing the number of people aged 14-35 with possible psychosis presenting to mental health services for the first time. Information from this audit should then be used to develop an implementation plan and be reported in the comprehensive review of services.

## **Main findings**

1. The projected annual rate of first-episode psychosis to secondary care is between 50 and 70 cases for the Wakefield & Pontefract area.
2. The average age at first-episode onset is 22 years – 75% were under 24 years of age, with as expected twice as many male referrals as female.
3. 49% of the sample did not possess any educational qualifications. None were in paid employment, undertaking vocational training or in further education.
4. 58% of clients initial referral to secondary services is through their GP although 25% of the clients were referred from hospital casualty departments, and a similar proportion will have other undesirable pathways to care such as contact with the Police.
5. The average duration of untreated illness was 16 months (range 12 weeks-2 years). The duration of untreated illness is seen as the strongest predictor of outcome for first-episode psychosis and in this study did relate to the use of MHA but not to enhanced care planning following discharge.
6. 77% of the audit sample were detained under the MHA(1983) and this was found to be commoner if the person was a male or living alone. The strikingly high level of legal detention is comparable to other studies, and probably represents the norm.
7. Clients with a duration of untreated illness (DUI) of greater than twelve months were far more likely than those with a shorter DUI of being detained under the Mental Health Act.

## **Implications**

The audit findings are important considerations for early intervention service development and its continuation and further study is necessary to clarify these results further.

The duration of untreated illness (DUI) is proving to be a key mediator of desirable and undesirable experiences in the first-episode psychosis sample. Achieving shorter DUI will decrease the duration of hospital admissions, lower the need for use of the Mental Health Act and shorten the lengthier pathways into secondary care. The need for early detection training in primary care to facilitate a decrease in DUI is highly appropriate. Clear deficits in employment and educational goals are evident even at this early stage of the serious mental illness trajectory.

## **Summary**

In the Wakefield and Pontefract district new clients can be ill for as long as two years before being offered a service and then treatment by compulsion is common. A large proportion of local users access services through circuitous and undesirable pathways, often after a long delay and under coercion. The literature points to this kind of early experience of services as formative and provokes both treatment reluctance and service disengagement which unfortunately is the norm throughout the UK (Birchwood et al 2000).

Three principal requirements emerge for changing services given to young people with psychosis and their families;

- Improved primary care knowledge and skills about early detection and value of evidence based interventions in the early phase of psychosis,
- more acceptable secondary care responses for young people,
- better integration of primary and secondary care.

## **Recommendations**

All clients during their first psychotic episode receive a specific service that can provide a rapid and easy access to specialist assessments, with initiation of treatment in a setting which does not have stigma attached to it, and comprehensive psychosocial interventions and support.

The development of close links between psychiatrists, primary care professionals, service for those who misuse substances, and educational and vocational services will help clients to be diagnosed early and allow them the benefit from continuing treatment and rehabilitation.

Service development requires a radical re-think of current approaches one that recognises the potentially serious and debilitating nature of psychotic illness and that it is often the social consequences of psychosis which are the most damaging.

A service model with a greater emphasis placed upon the adoption of best practice, the building of new professional relationships and partnerships as well as the adoption of a recovery model which puts clients needs, aspirations and lifestyle at the centre of all planning is therefore strongly recommended.

A combination of expert specialist treatment and models of care which focus on the psychosocial needs of service users is required if we are to significantly improve individuals' experience of psychotic illness and achieve genuine improvements in long term outcomes

The project has also identified a number of nationally and locally driven agendas and initiatives that have overlapping or parallel objectives. Wherever possible the project has sought to contribute to working jointly with appropriate projects and partner organisations. These include:

- Mental Health Promotion strategy (NSF standard 1)
- Primary Care protocols for mental health
- Crisis Resolution and Home Treatment (DOH PIG)
- Healthy Schools standard
- Healthy Care standard
- Connexions
- CAMHS strategy
- National anti-drugs strategy (Home Office)

## **2.0 Background and Introduction**

Early intervention in psychosis “amounts to firstly deciding if a psychotic disorder has commenced and then offering effective treatment at the earliest possible point; and secondly ensuring that intervention constitutes best practice for this phase of illness, and is not just the translation of standard treatments developed for later stages and more persistently ill subgroups of the disorder” (McGorry et al, 1996 p. 305).

Worldwide there is an average delay of between one and two years between onset psychosis and starting treatment (Lieberman and Fenton 2000). A number of causes and influences have been proposed to explain these delays; difficulties of diagnosis, lack of psychosocial support, poor premorbid functioning and stigma may all play a role in discouraging people from seeking help and delaying treatment. Treatment is rarely initiated until a person experiences a frank psychosis, and even then a diagnosis may not be straightforward.

From a strategic level, improving health outcomes, the effective use of resources, clinical accountability, and education and training form part of the UK’s National Health Service statutory obligation of clinical governance. (DOH, 1997).

In line with clinical governance effective clinical practice should be informed by research evidence, identifying optimum interventions for patients presenting with clinical conditions. Best evidence should be translated into guidelines to aid practitioners with their practice, with this iterative process becoming a part of routine practice and local evidence based cultures.

With regard to an evidence-based culture, initial literature searches reveal that there are many changes and developments in the field of early intervention that are guided by new research evidence regarding good practice and particularly the effectiveness of certain interventions.

Interventions in psychosis whether biological or psychosocial, have historically been blind to the phase and age of the illness with a ‘one service fits all’ approach.

Hundreds of families throughout this district, thousands throughout the country and millions around the world know that a psychotic disorder can strike just as their teen-aged sons and daughters are poised to advance in education, start a career, or develop



adult lives, and the results have often been a quick descent to severe disability that can last a lifetime and devastate the family.

The evidence that the first episodes of schizophrenia and other functional psychotic illness present in youth, disrupts the lives of the individual and their friends and relations, with slow and often traumatic engagement in treatment is irrefutable as is the powerful consistent correlation between a longer period of untreated illness and a poorer outcome, including a greater risk of relapse.

Until relatively recently, the traditional view of the diagnosis 'schizophrenia' was seen as tantamount to a sentence of life with an all-consuming brain disorder. More contemporary perspectives, both national and international suggest that early access to treatment is the vital linchpin for these young people. The new paradigm of early intervention argues that the early phase of psychosis is a major influence representing a formative and indeed 'critical period' with important implications for secondary prevention of the impairments and disabilities that accompany psychosis.

The possibility of preventing the development of some of the secondary disability and handicap, together with a recognition that young people at this phase of life may have special needs in the context of a serious mental illness justifies a separation from patients with more established illnesses; such 'streaming' would facilitate better understanding of their needs.

To enforce positive changes for young people with psychosis, this district needs to develop an innovative 'age and need appropriate' early intervention service. Although there is a clear rationale for early intervention, attempts to improve early detection and treatment face many challenges. The duration of untreated psychosis is probably influenced by many factors, such as pattern of onset of psychosis, tolerance of abnormal or eccentric behaviour in the patient's social network, social and cultural factors such as the stigma of mental illness, accessibility of appropriate care, the skills and knowledge of health care and counselling professionals in primary care settings, and the degree to which afflicted individuals and their families accept available treatment.

It is clear that a range of psychosocial interventions of proven and growing effectiveness, along with service models through which these interventions can be deployed, are now available for this client group. Focusing on early detection and

intervention can offer the opportunity to make a real difference to the lives of young people with psychosis and their families.

The project will be at the forefront of the developments in Early Intervention within the Northern and Yorkshire region and in accordance with Department of Health directives, it will establish an empirical sound evidence-base for the development of a local early intervention service for first episode cases of psychosis.(DoH 2001).

## **2.1 Aims and objectives of the Project**

This project should be viewed as the initial phase of a larger long-term initiative aimed at developing the capacity of the current mental health services to identify people experiencing a recent onset/first episode of psychosis, and to provide early and effective evidence-based interventions for those individuals and their families.

To generate local interest in establishing a cohesive and agreed strategy, which will provide the basis for the development and implementation of a local service model for early intervention in psychosis.

The early intervention project recognises that local action is critical in delivering modern services where strong local partnerships and working arrangements are required for the service to operate successfully, and is committed to improving the mental health of people in the district by developing an evidence based service that will meet the identified local needs.

## **2.2 Health Action Zone Fellowship**

This report was published as part of a Health Action Zone Fellowship; the opportunity to undertake the Fellowship arose in July 2000. Health Action Zone (HAZ) status has been awarded to twenty-six areas in England identified as 'areas of pronounced deprivation and poor health' (NHS Executive, 1997). The HAZ is a partnership between the National Health Service, Local Authority, the voluntary and private sectors and local communities, and is required to produce a programme for action to achieve national and local objectives of this public health initiative. Basically the Zones were set up in the most deprived areas of the country as a new way of tackling inequalities in health and to improve the health of the worst off.

### **2.3 Area covered by the Health Action Zone**

Wakefield is one of five metropolitan Districts that make up the West Yorkshire conurbation. Wakefield and District has a population of approximately 330,000 people and includes people in the parliamentary constituencies of Hemsworth, Pontefract and Castleford, Normanton and Wakefield. The Wakefield and District area covers approximately 130 square miles. It contains a mixture of urban and rural areas, and a number of distinct communities within its boundaries. There is a diverse range of economic, cultural and environmental characteristics with some areas experiencing severe deprivation alongside areas of relative affluence.

In the west of the District are the City of Wakefield, the former County Town of West Yorkshire, and the towns of Ossett and Horbury. Wakefield remains an important regional administrative and commercial centre. The north east of the District contains the five towns of Castleford, Pontefract, Normanton, Featherstone and Knottingley, and is designated in the Local Authority unitary Development Plan as a Regeneration Area. The southeast contains the communities of Hemsworth, South Kirkby and South Elmsall, Ryhill, Fitzwilliam and Upton, which are also designated a Regeneration Area.

The Overall Index of Multiple Deprivation (2000) showed the district to have some of the most deprived wards in England. It shows that two of the District's wards fall within the most deprived 5% and that a total of five wards are within the 10% most deprived in England.

According to the 1991 Census, 98.5% of the population are of white ethnic origin. The ethnic minority population is half of (UK) Pakistani origin with smaller numbers of Bangladeshi, Chinese and West Indian and African origin.

Studies show that on a local level there are higher levels and earlier onset of drug use than might be expected from the national data, evidence suggests that the level of heroin use among young people in the Wakefield and Pontefract area is higher than the national average. Cocaine and crack use in the area appears to be rare, although its use is possibly under reported. There are four main sources of information for our local area: a regional school survey, the Substance Misuse Database, agency statistics and police statistics.

Indicators of social inequality at birth are associated with increased risk of adult-onset schizophrenia, suggesting that environmental factors are important determinants of schizophrenic disorders. People with schizophrenia are more likely to occupy lower socio-economic positions and reside in areas characterised by higher social deprivation at the time of first diagnosis (Croudace et al, 2000; Eaton & Harrison, 2001). It is unclear whether these factors contribute to aetiology or whether they result from social segregation caused by prodromal symptoms.

Studies suggest a high comorbidity of substance abuse and schizophrenia Reiger et al (1990) and a high incidence of substance abuse in first-episode patients Hambrecht & Hafner (1996). Comorbidity of substance abuse and schizophrenia has been associated with poorer compliance, a higher rate of relapse, more positive symptoms and disorganization, more depression and cognitive impairment, poor treatment response and poorer outcome . Owen et al (1996), Gupta et al (1996)

The social environment generally is a vital part of the picture of many problems, including problems with both physical and mental health. People living in deprived inner-city areas are much more likely to be given a diagnosis of schizophrenia than people living in more affluent suburban areas. Faris and Dunham's social isolation theory suggested that poverty and social isolation were likely to trigger psychosis in vulnerable individuals.

A second theory, the social drift theory, suggests that people who are given a diagnosis of schizophrenia might be born in any socio-economic environment. However, the development of psychotic experiences (and the effects of treatment) is likely to prove disadvantageous for social functioning and employment opportunities. People with such problems therefore are likely to drift into lower socio-economic circumstances and end up in poor housing and employment. What is clear is that poverty and the diagnosis of schizophrenia are related, but whether as cause or effect is unknown. (Freeman, 1994, Fox, 1990)

The South West Yorkshire Community NHS Trust provides mental health and learning disability services to a population of approximately 320,000 people in the Wakefield Metropolitan District and has a budget of £45 million. It employs approximately 2,000 staff, which work across a wide geographical area and have varied professional backgrounds. The services include community and residential

care for people with a learning disability, including respite care, therapy services and community homes. Community residential and day care services are provided for people with a mental illness, including crisis services, respite care and services for people who need care in a secure environment. Other services include family, children and specialist services.

## **2.0 Literature Review**

The following literature review provides a summary of the information and evidence relating to psychosis, its early detection and treatment. The search was conducted using various methods. Database search included MEDLINE, CINAHL and the British Nursing Index. The Internet provided access to a range of web sites and the library material was accessed via the Leeds Metropolitan University reference system.

### **3.1 Rationale for achieving earlier intervention for this client group**

There are compelling arguments, both at an ethical and moral level and supported by research, for developing primary and secondary services which can better target the needs of young people and promote early intervention to reduce the impact of schizophrenia and other allied major mental illnesses. These can be summarised as;

The impact of psychosis on an individual, their family and friends is profound and early diagnosis and treatment of the first episode may offer a significant opportunity to improve the prospects of recovery and reduce longer-term impairment (Birchwood et al 1997). For most GPs a variety of presentations and only a frequency of between half and two cases per year makes initial diagnosis difficult and requires GPs to maintain a high index of suspicion. The average age of onset of schizophrenia and manic-depressive disorder is 19 years, and 80% are aged between 16 and 30 at presentation (McGorry et al 1997).

Inappropriateness of services and issues of stigma may cause young people to be reluctant to use existing specialist services and thus compound delay. When young people with emerging psychosis experience delays of more than 6 months before engaging in treatment, the chances of early recovery, good quality remission and a long relapse free period are all reduced (Drury et al 1996; Loebel et al 1996).

These are major effects - relapse is three times commoner in the ensuing 2 years, independent of prophylactic medication, if the duration of untreated illness exceeds 6 months (Johnstone et al, 1986).

### **3.2 The Policy Context**

The long-term course of schizophrenia and related psychotic disorders are increasingly seen as one of the world's most serious public health problems, and generally regarded as one of chronicity and disability. It affects one in every 100 people at some point in their lives. There are around 250,000 patients in the UK at any time, across all social classes and cultures. It imposes a burden not only on the individuals, but also on families, carers, friends, the health service and wider society. It is certainly an expensive illness to treat, with estimates of more than 5% of the total NHS in-patient expenditure. (Knapp1997).

Despite the availability of treatment, more than 50% of patients continue to exhibit moderate levels of "positive symptoms" such as delusions, hallucinations, and disorganized thinking and behaviour, and "negative symptoms" such as poverty of thought, volition and affect, and social and interpersonal withdrawal, and require long-term support and periodic admission to hospital. (Awad and Hogan, 1994). It is therefore important to find ways to improve long-term outcome.

Most observers of patients with schizophrenia would agree that identifying and treating the disorder generally enhances the patient's symptoms. However, diagnosis and treatment can also negatively affect quality of life: the medications used to treat schizophrenia often have adverse side effects that decrease functioning, increase stigmatising involuntary movements, and impair ability to interact socially.

Additionally, many people diagnosed with mental illnesses suffer from the social stigma (and resulting isolation) associated with being so identified. Brown et al (1998), Rogers et al (1998).

In the NHS plan the Government identifies that by 2004 all young people who experience a first episode of psychosis, such as schizophrenia, will receive the early and intensive support they need, and estimates that this will benefit 7,500 young people each year.

The government's strategy document highlights the importance of early intervention:

*“ Early intervention matters to prevent relapse, reduce the risk of suicide and ensure public safety”*

*“Fifty early intervention teams will be established by 2004 so that young people with first episode of psychosis will get the help they need”.*

The National Plan for the NHS

### **3.3 What is Psychosis?**

Psychosis is a condition characterized by impairment in reality testing and may involve severe disturbances in perception, cognition, behaviour, and feeling. It is a serious but treatable condition. There are multiple causes of psychosis, which include substance abuse or withdrawal, exposure to severe stress, inherited and acquired medical conditions or diseases, and mood disorders. The onset of schizophrenia most often occurs during the late teens or early twenties. The diagnosis of schizophrenia is seldom made in prepubertal years. In part, this is due to the current uncertainty in interpreting symptoms of abnormal cognitive and behavioural functioning at this age. Therefore psychosis can be viewed as a young person’s illness; the average age of onset is in the teenage years. It is the most debilitating of the psychiatric disorders, particularly of young males and can have far reaching implications for the individual sufferers, their families and friends. . It is well documented that the emergence of a psychotic illness generates acute distress and confusion in the individual, their families and friends. (Robinson et al, 1999, Hafner et al, 1995, (Birchwood et al 2000).

The onset of the illness is often at a critical period of the person’s development and can have debilitating affect on all aspects of their life. Untreated psychosis is linked with considerable distress, suicide and with increased probability of early relapse and residual symptoms as well as been associated with longer first and second admissions to hospital and substantially higher health care costs.

At present it can be up to two years before a person with untreated psychosis begins to receive the appropriate help and treatment. Harrison et al, (1996) describe the early phase of psychosis as stormy, plateauing thereafter, this is why the first 3 years of psychosis has been characterised as a ‘critical period’ as it carries with it the highest

risk of relapse, suicide, disability but also treatment reluctance and service disengagement (Birchwood et al, 1997).

Social and personal disability develops aggressively in the 'critical period', unemployment, impoverished social network, loss of self esteem can develop aggressively during the critical period; the longer these needs are not dealt with, the more entrenched they become. (Birchwood et al, 1998).

### **3.4 Incidence and Prevalence of Psychosis.**

Different researchers have recorded different estimates of the incidence of schizophrenia using traditional medical definitions of the problem. Generally there is a consensus that about one person in a hundred will be diagnosed with schizophrenia during their lifetime, this statistic has been substantiated by the World Health Organization. The prevalence of the disorder (a slightly different statistic reflecting not an individual's risk, but the proportion of people experiencing problems at any one time) is estimated at between 0.2 and 1 per cent. It tends first to be diagnosed in early adulthood (late teens and early twenties). This means that, in the UK, between 100,000 and 500,000 people are experiencing such problems at any one time. Schizophrenia is usually reported as slightly more common, and possibly more severe, in men, although this may be in doubt. The majority of men who develop the problems that lead to a diagnosis of schizophrenia do so before the age of 25. Women tend to develop problems about five years later, although there is a very high level of variability.

About one person in a hundred is likely to receive a diagnosis of schizophrenia. In the UK, between 100,000 and 500,000 people are experiencing a psychotic illness at any one time.



### **3.5 Psychosis Damages Psychosocial Development**

The heterogeneity of psychosis is well documented and the influence of socio-cultural, psychological and biological factors on psychosis is now increasingly understood. It disrupts a young person's life at a critical stage of social and psychological development. Social development is harmed as symptoms interfere with peer relationships and lead to social isolation. School and work performance declines, and there can be a profound loss of social and economic potential.

Family relationships suffer as both the individual experiencing psychosis and family struggle to understand and cope with the changes. Secondary psychiatric problems such as depression and substance abuse often develop. The risk for suicide increases dramatically in people who develop psychoses. The consequences of psychosis can have extremely serious effects on the individual and their family. These consequences may be more important in the so-called deteriorative process than the illness itself. Given that a first psychotic episode is likely to occur in adolescence and early adulthood, the disruptions caused by unrecognised and untreated symptoms can alienate the young person from their family and friends and disrupt their education and vocational functioning. The ensuing social exclusion that includes disruption to social networks, educational and vocational development and to personality formation can create major difficulties for the young person trying to establish identity and direction in life. For families who often do not understand exactly what is occurring, a great deal of distress results. Family conflict which exacerbates stress at home in turn impacts negatively on the individual experiencing psychosis. Delayed treatment is more likely to be associated with police intervention and compulsory admission to psychiatric hospitals established to deal with older chronically ill individuals. These aspects of treatment are obviously traumatic for the individual and their families and post traumatic stress disorder may be an outcome of the experiences. Other types of secondary effects include, social anxiety, depression, substance abuse and homelessness (Bowers 1965, 1968; Bowers and Freedman 1966; Stein 1967, Loebel et al. 1992).

Many abnormal biological features usually seen in people with well-established schizophrenia can also be seen in a subgroup during their first psychotic episode. It is

widely assumed that psychotic experiences have some kind of biological cause, although precisely what this is, is not known and may never be understood. It is clear that psychotic experiences involve brain events, and can be influenced by chemical processes, however every thought process involves chemical changes in the brain.

The stress-vulnerability model suggests that both psychological and biological factors may leave some people more vulnerable than others to environmental stressors.

Although this does not explain what a psychotic experience is, it can help people to understand how both biological and psychological factors can contribute to problems.

It suggests that vulnerability will result in the development of problems only when environmental stresses are present. If the vulnerability is great, relatively low levels of environmental stress might be enough to cause problems. If the vulnerability is lower the individual is more resilient and problems will develop only when higher levels of environmental stress are experienced. This helps to explain why some people develop problems and others do not, even when they experience similar traumas.

Most evidence suggests that the cognitive problems associated with schizophrenia emerge at the onset of psychosis and quickly stabilise.

Early use of the mental health act and high doses of neuroleptics with side effects have been shown to increase later treatment reluctance and service disengagement. Approximately one third of patients hospitalised for an acute psychotic episode show symptoms of post traumatic stress disorder (PTSD) related to their psychosis and its treatment (McGorry et. Al, 1991).

People with a psychiatric diagnosis are arguably one of the most socially excluded groups in society. Social roles and goals, particularly work are highly prized by young people and may build self-esteem that can impact on the psychosis itself (Warner, 1994). Unemployment, impoverished social networks, loss of self esteem will develop aggressively during the critical period. ( Birchwood, 1998; Mason et al, 1995).

The longer the delay before resumption of work, or continuation of the path to work, the greater the likelihood of long-term difficulty.

Adverse outcomes from psychiatric hospitalisation suggest the need to stream the treatment naive patient into a special environment.

### **3.6 The Importance of Early Intervention**

The importance of early detection and treatment of psychotic disorders has been raised in psychiatric literature for some time. Cameron wrote of the need for a preventive approach to schizophrenia (Cameron 1938). He called for “the detection of very early disorder to prevent later serious ill health”. More recent authors have also stressed the need for early diagnosis and management in schizophrenia to reduce or prevent the psychological and social disruption that results from psychosis (Falloon 1992; Birchwood and MacMillan 1993).

Today the justification for early intervention in psychosis is considerable. The delay between onset of psychotic pathology and the first treatment is estimated at between 1 to 2 years (McGorry & Jackson, 1999; Birchwood, Todd & Jackson, 1998). The duration of untreated psychosis (DUP) has been shown to be related to poor long-term outcomes, lengthier hospital admissions (Wiersma et al, 1998), and longer-term treatment resistant symptoms (Harrow et al, 1995). Furthermore, the early phase of psychosis is a “critical period” for intervention, for example 30% of individuals are at risk, either as a danger to themselves or due to attempted suicide (Lincoln & McGorry, 1999; Birchwood, McGorry & Jackson, 1997); the critical period is the primary phase for the development of the major long-term disabilities associated with psychosis, for example, unemployment, lack of social support, poor self-esteem, etc, and the initiation of the “revolving door” pattern of admission (Mason et al, 1995).

The primary aim of an Early Intervention Initiative is to enhance the recognition of early signs and symptoms of psychosis and improve the services intervention capability. Early diagnosis and treatment can lead to significantly improved recovery and outcome. By contrast, the longer the illness goes untreated, the longer it takes for remission of symptoms, the lesser the degree of remission, and the greater the chance of early relapse. Because of the damage caused when the early signs of psychosis are ignored, efficient methods must be established to ensure that individuals are helped as soon as possible. Help must be provided with compassion and respect, further traumatizing the person will create more problems and can lead to early treatment withdrawal.

### 3.7 Why intervene early in psychosis?

Delay from onset of symptoms to first treatment is often long: Numerous studies have now confirmed early observations that the interval between first signs of psychotic symptoms and first treatment is one to two years. (Birchwood et al, 2000).

- The early years of psychosis constitute a psychosocially 'critical period'.
- The longer psychosis remains untreated, the greater the risk of serious physical, social or legal harm:
- The period of untreated psychosis has been shown to distress individuals and their relatives, revealing ineffective and demoralising attempts to get help and various traumatic events.
- 20 to 30% of patients with first episode psychosis are a danger to themselves or others, before receiving effective treatment.
- Psychosis links with a variety of well documented problems, including substance misuse, depression and suicidal thinking, social avoidance and Post Traumatic Stress Disorder-like phenomena. These may reflect difficulties individuals face in coming to terms with their psychosis and the manner of its treatment, leading to loss of valued social roles and personal identity (Rooke and Birchwood, 1998).
- 10% to 15% of people with psychosis commit suicide, highest risk being early in the illness (two thirds within the first 5 years). Suicide is preceded by such factors as depression and particularly hopelessness, potential targets of psychosocial interventions.
- Suicide is linked to repeated readmission in the critical period.
- Delay in the treatment of psychosis has been associated with substantially higher health care costs for at least three years after first treatment. Studies have shown that long untreated illness is associated with longer first and second admissions (Wiersma et al, 1998), giving rise to higher healthcare costs.
- Long term 'treatment resistance' develops during the critical period (Mason et al, 1995). Frequent, and/or long untreated episodes of psychosis risk further relapse; and the presence of more than one relapse and residual symptoms in the first two years is a major prognostic factor in its own right (Mason et al, 1997).

### **3.8 Early Warning Signs of Psychosis**

The onset of psychosis may be abrupt, but typically is preceded by changes in functioning that may last for weeks, months or even years. Families and friends usually have a vague but distinct awareness that the person's behaviour has become "unusual" and that the person is "not the same." The number, duration and severity of these signs differ from person to person. Today schizophrenia is generally considered to result from a combination of environmental stress and an inborn vulnerability to psychosis. It is usually expressed in late adolescence as manifested in cognitive and social impairments. The presence of a deficit process has been clearly demonstrated at the onset of positive symptoms of schizophrenia, however when and whether these deficit processes are present in the prodromal phase is unclear.

The term "prodrome" has been used by some authors to denote the pre-psychotic period before a relapse in those patients with established psychotic illnesses (Herz and Melville 1980; Birchwood et al. 1989; Malla and Norman 1994). A "relapse prodrome" should be distinguished from the pre-psychotic period preceding the first onset of a psychotic illness, the "initial prodrome." In this report, the term "prodrome" is used instead of the longer "initial prodrome." Initial prodrome is defined as the period of time from the first change in a person until development of the first frank psychotic symptoms. In essence, the prodrome is the period between the most valid estimates of the onset of change in the person and the onset of psychosis. Changes generally occur gradually, and the point of departure from the patient's normal level of functioning - the onset of the prodrome—may be difficult to pinpoint for both patient and informant. The point when changes could be called "psychotic" the offset of the prodrome and onset of psychosis—may also be difficult to accurately define. The boundary between "different but not psychotic" (or "prepsychotic") and "frankly psychotic" can be and are often blurred.

Mrazek and Haggerty (1994) believe that the best hope for the prevention of schizophrenia lies with indicated preventative interventions targeted at individuals manifesting precursor signs and symptoms who have not yet met the full criteria for diagnosis. The identification of individuals at this early stage, coupled with the introduction of pharmacological and psychological interventions, may prevent the development of the full-blown disorder.

Strategies for reducing the duration of untreated psychosis that could be evaluated include teaching better methods of case detection at the primary care level, increasing awareness of psychosis among the public and targeting high-risk populations for early case detection and intervention. It has been proposed that “indicated prevention” efforts be directed toward people who are at high risk and who show minimal, yet detectable, signs and symptoms, but who do not meet the criteria for schizophrenia. The definition of “caseness” — the point at which a patient can be regarded as suffering from psychosis and in need of treatment — would have to be adjusted, so that treatment for psychosis could be initiated even in the absence of a definitive diagnosis of schizophrenia.

Several attempts are under way to examine strategies to prevent schizophrenia in highly susceptible individuals. However, we must await more definitive evidence from controlled trials of psychosocial and pharmacological interventions before such strategies can be implemented.

It is felt that realistic prevention in early psychoses can occur within three related foci:

- the pre-psychotic phase .
- early detection of fully fledged psychosis and intensive treatment of the first episode.
- subsequent recovery or critical period.

Mrazek and Haggerty (1994).

Interest in the early detection and treatment of psychosis has recently turned towards the possibility of primary prevention of schizophrenia and related psychoses.

McGlashan noted that primary prevention in mental health involves reducing the occurrence of new cases (i.e. incidence), while secondary prevention aims to delay onset or prevent recurrence (i.e. reduce prevalence), and tertiary prevention aims to decrease the duration or severity of symptoms and associated disability. (Harris 2000). Three strategies have been proposed to achieve the primary, secondary and tertiary prevention of schizophrenia and related psychoses. (Fallon 2000). These are: (i) the early detection of groups at increased risk of developing a psychotic illness; (ii) the early treatment of first episode psychosis; and (iii) targeting interventions at the early ‘critical period’ of psychosis. In terms of primary prevention, it has been

proposed that if the distinguishing features of those people who subsequently develop psychosis can be identified, then it may be possible to prevent the development of frank psychotic symptoms . Therefore, the main focus of primary prevention studies of schizophrenia has been to develop strategies and criteria for the identification of groups at increased risk of developing a psychosis.

Although getting help early involves recognising psychosis at the earliest possible time and finding appropriate specialist treatments, for now, it may be more productive to improve detection of already established psychosis and initiate early treatment;

- “Schizophrenia does not present in neat parcels” (Tara et. al., 1994) This is relevant particularly to the early phase of psychosis where diagnostic reliability is modest at best, and the longitudinal stability of symptom presentation are low (McGorry 1991,1992).
- Such uncertainty in diagnosis should not delay treatment, but a symptom based approach to treatment needs to be taken. The use of a working diagnosis of “psychosis”, and avoidance of a syndromal diagnosis until symptom stability emerges (usually within the first 2 years of treatment) does not represent clinical or intellectual sloppiness, but a genuine response to the reality of the clinical situation.
- The embracing of diagnostic uncertainty needs to be observed.

### **3.9 Psychological interventions**

The treatment of psychotic disorders has been revolutionized by modern pharmacotherapies in the past half-century (Baldessarini, Tarazi, 2000). However, these treatments have strongly encouraged contemporary psychiatry to explain these complex disorders biologically and to treat them with maximum apparent cost efficiency (Baldessarini, 2000). An associated trend is to undervalue and under-utilize psychological / psychosocial interventions in the treatment and prevention of these disorders, despite growing evidence that such methods can significantly augment the effects of pharmacotherapy alone (Huxley et al., 2000).

A recent review of psychotherapy in the NHS found talking treatments to be as important a component of healthcare as medication, but also found that such treatments are often not available to people who have psychotic experiences. Currently, most people who have psychotic experiences and receive talking treatments also receive medication. However, research in the United States has suggested that for some people, psychotherapy can be more effective without medication, and that it can sometimes be more effective than medication alone.

People may find medication helpful when in acute distress, but do not want to take it long-term. Some psychologists feel that psychological interventions could offer an alternative to long-term medical treatment for some people. The integration of medical, psychological and practical approaches echoes the growing recognition that social and psychological factors interact strongly with biological factors in psychotic experiences.

Many individuals with psychotic experiences have complex difficulties. The psychotic experiences themselves, the framework within which people understand them, their coping responses as well as the disruptions of relationships and social networks, and the depression and anxiety that can follow are all important. All these demand a careful therapeutic response.

The literature points to a number of interventions now available that can alter the trajectory of psychosis. These include;

psychosocial interventions, family work, cognitive behavioural therapy and medication.



### **3.10 Psychosocial Treatments in Psychotic Disorders**

Clinical research over the past two decades has provided support for these approaches. (Huxley et al., 2000). Various theoretical approaches to individual therapy have been studied in the treatment of schizophrenia and related psychotic disorders. Although psychodynamically based techniques were common in the early 1900s, individual therapy was given strong encouragement in the 1970s due to the development of a social skills training approach designed specifically for chronically psychotic patients (Hersen and Bellack, 1976; Hogarty et al., 1986). Social skills training was generally helpful in enhancing specific behavioural skills, but it was criticized for its narrow benefits and limited generalizability to daily living. Use of psychosocial interventions in chronic psychotic disorders has resulted in clinical improvement in a range of outcome measures. (Huxley et al., 2000).

These include:

- support and encouragement arising from interactions with others having shared experiences;
  - education of patients and their families to encourage collaboration in treatment;
- more effective identification and management of adverse effects of medication that tend to limit its acceptance;
- increased compliance with recommended medication;
- enhanced detection of early signs of impending illness and improved skills aimed at minimizing stressors contributing to recurrence risk;
- improved interpersonal and family relationships affected by the illness, and promotion of higher functional achievements.

It is increasingly recognised that psychosocial interventions can reduce the probability of psychotic experiences returning, and can reduce 'relapse rates' by as much as 50% . (Hogarty & Ulrich 1998)

More recently, cognitive-behavioural therapy techniques have been studied in the treatment of schizophrenia with encouraging findings in symptom reduction when compared to standard medication treatment. (Huxley et al., 2000; Serok and Zemet, 1983).

### **3.11 Cognitive Behaviour Therapy (CBT)**

The British Psychological Society (2000), has reported that CBT has proved promising as a psychological intervention for psychotic experiences. The main assumption behind CBT is that psychological difficulties depend on how people think or interpret events (cognitions), how people respond to these events (behaviour), and how it makes them feel (emotions). CBT aims to break the vicious cycle between thoughts, feelings and behaviours by helping people to learn more useful ways of thinking and coping.

Although people occasionally have hallucinations, which may be visual (seeing things), olfactory (smelling things) and tactile (feeling things), psychological interventions so far have concentrated on voices (auditory hallucinations). Although the phenomenon and its causes are complex, it is now a generally accepted viewpoint that some people who hear voices have difficulty distinguishing their own thoughts or inner speech from voices with an external origin. It is known that hallucinations tend to be worse when people are highly aroused. It is also known that people's beliefs and explanations about their voices affect how distressed they become. These findings suggest that therapy should address problems in identifying where voices are coming from, should reduce stress or arousal, and also address beliefs about the experiences. The personal meaning and relevance of voices in a person's life may be addressed during therapy if the person feels this is relevant. The use of CBT for voices is relatively new, but comprehensive reviews have concluded that CBT for hallucinations is effective .

CBT is a tried and tested intervention that examines patterns of thinking associated with a range of emotional and behavioural problems.

Quality of remission and length of relapse-free period are improved by cognitive behavioural therapy as an adjunct to neuroleptic treatments (Drury et al 1996).

Cognitive therapy shows considerable promise for drug resistant symptoms (Garety et al, 1997) and should be considered.

### **3.12 Family interventions**

Family therapy has shown particular promise in schizophrenia since the 1960s. This treatment emerged from awareness that families experience considerable stress from living with a psychotic relative, and that distress and negative attitudes within families are strongly associated with risk of clinical worsening (Nugter et al., 1997). Studies of treatments of both single- and multi-family therapies, usually involving patients living at home, demonstrate that these approaches can similarly and significantly augment pharmacotherapy. Reported results include symptomatic improvement, improved social and vocational functioning, and lower relapse rates (Zastowny et al., 1992; Zhang et al., 1998).

Clinical psychologists have been able to develop therapeutic approaches that offer help to carers and are designed to improve these relationships. Family interventions can reduce the frequency of episodes of psychotic experiences and improve people's employment prospects. Such approaches have also been found to reduce stress in other members of the person's family. Not all people who have psychotic experiences live with their families, relationships with staff and carers are subject to the same factors. It has also been suggested that mental health teams need to train, supervise and support staff and carers to reduce the potentially negative effects of unhelpful relationships. Although family interventions are effective and save money, they are uncommon in routine practice, and remain an effective but underused intervention. Effective family interventions have been developed and should be made available routinely (Mart et al 1996).

### **3.13 Medication**

The primary medical response to schizophrenia is the provision of medications. There are over 30 different antipsychotics available and nearly all acute psychotic episodes require antipsychotic drugs for control.

The limitations of neuroleptic therapy include a relative lack of efficacy in treating psychosis in a substantial minority of patients; the limited effect of these drugs on negative symptoms and cognitive deficits, such as those affecting verbal working memory and executive functioning; and the tendency of these drugs to induce disabling and distressing side effects, such as parkinsonism and tardive symptoms. The recent introduction of "atypical" antipsychotic agents such as clozapine,

risperidone, olanzapine and quetiapine provides new hope for patients because of the lower incidence of extrapyramidal side effects associated with these compounds and their possible efficacy in treating negative and disorganization symptoms and improving verbal working memory.

Research points to early neuroleptic treatment leading to improved outcomes.

(Waddington, Youssef and Kinsella 1995, Wyatt 1991). New atypical anti psychotic medication offers the hope of reduced secondary symptoms and speedier recovery as well as lowering the suicide rate among longer-term treatment-resistant patients (Bosanquet 2000).

McGlashan (1996) proposed an early detection hypothesis as follows:

*'Reducing the duration of untreated psychosis by providing effective treatment with neuroleptic medication plus psychosocial management will result in an improvement in both short and longer term outcomes, compared to what would have otherwise occurred.'*

Antipsychotic, mood-stabilizing and antidepressant drugs can be effective in managing many prominent and distressing symptoms of psychotic disorders, but as many as one-third of medically treated patients diagnosed with schizophrenia or bipolar disorder relapse within two years of an index hospitalisation (Hogarty, 1984; Baldessarini et al., 2000).

Moreover, the limited but potentially modifiable tolerability of most antipsychotic agents limits their long-term acceptance and thus their actual effectiveness (Baldessarini, 1994). The fact that medications alone may not be able to optimise coping abilities or address the personal, social and functional complications of having a major mental disorder indicates the potential importance of adjunctive psychosocial treatments in a sound, comprehensive program of clinical care.

An encouraging and growing body of evidence supports the implicit thesis that, when combined with appropriate pharmacotherapy, well-designed psychosocial interventions can enhance clinical outcomes cost-effectively. Benefits are particularly likely for outcomes based on measures of functioning or satisfaction and sparing of rehospitalization, as well as on symptom-oriented assessments. Psychosocial treatments that are widely employed and increasingly investigated for patients with psychotic disorders include individual, group and family therapies.

Long duration of psychosis before commencing neuroleptic medication consistently relates to poorer long-term outcome: conversely early treatment improves outcome (Wyatt, 1996). Adherence to medication regimes and developing an acceptable quality of life are likely to be hindered by uncomfortable medication side effects (McGorry et al., 1996). Such distressing side effects occur more commonly in first-episode psychosis clients than they do in clients with established illness (Emsley et al., 1995).

Outcome studies in the service delivery setting (McGorry et al., 1996), medication trials (McEvoy et al., 1991; McGorry et al., 1997) and neuro-imaging studies (Kapur et al., 1996) have indicated that most people with first-episode psychosis will respond to doses of neuroleptics much lower than those conventionally used.

With sustained treatment over 85% of people achieve remission of symptoms from their first episode of psychosis within 6 months, most responding within the first month (Lieberman, et al., 1993; Syzmanski et al., 1996), so positive symptoms should not be allowed to linger.

### **3.14 Service models already established for achieving earlier intervention.**

Since the well-publicised service started in 1996 the TIPS project (Early Treatment and Intervention in Psychosis), in Norway focuses on a public health approach to achieving earlier intervention, using such devices as information and education programmes through local media, schools, primary care: facilitating access through phone help-lines with trained personnel. They report a 50% reduction in duration of untreated illness, gained essentially by enabling direct secondary access, but with the disadvantage that only 5 to 12% of the young people attending had psychosis.

Shepherd (1989) advocates integrating mental health services into primary care to achieve better community care. Falloon and Fadden (1995) have developed a radical service in Aylesbury, Oxfordshire that bases mental health services within primary care - described as integrated mental health care which attempts to support primary care with its range of mental health needs as well as evolve a service able to treat severe mental illness in a community setting. Falloon demonstrated marked consumer preference for an integrated care system of assessment compared to hospital based outpatient assessment, backed by attendance rates of around 95% for the former against 50 - 75% for the latter. The geographical area had an unknown level of inception, but Falloon observed marked reduction in expected levels of schizophrenia

and major affective disorder and concluded that this was due to integrated care achieving earlier intervention combined with optimal combinations of biomedical and psychosocial strategies.

Creed and Marks (1989) developed a model of liaison-attachment where the psychiatrist regularly meets with primary care staff to discuss management of shared clients and often carry out joint reviews with the GP. The GP continues to provide the client with treatment, but benefits from joint management plans and the ability to gain advice without necessarily referring a client. This allows a flexible specialist approach according to the needs of the case, reaches a wider variety of clients, and encourages better sharing of information and perspective between primary and specialist care.

McGorry et al (1996) have reported some encouraging results from their Early Psychosis Prevention and Intervention Centre (EPPIC) in Australia. The program encourages referral at an early stage, combines treatment strategies effective in the treatment of psychosis and aims for early reintegration of patients into the community. One of their studies compared outcomes of 51 patients with first-episode psychosis who were treated in the EPPIC program and those of a historical matched control group whose first episode was treated in a standard program (before the establishment of the EPPIC program). At the end of 1 year, patients in the EPPIC program had a lower number of hospital admissions, shorter length of stay in hospital, lower levels of negative symptoms, lower mean dose of neuroleptic drugs and higher scores on a measure of quality of life (all differences were statistically significant). Tentative, but not statistically significant, evidence indicated a reduction in the duration of untreated psychosis in the EPPIC group. The evidence suggests, therefore, that a change in the content and the timing of initial treatment of psychosis is likely to lead to better outcome for a number of dimensions.

Other studies from Melbourne, Australia show that early intervention can prevent deterioration and lead to a better long-term outcome. About 90% of patients achieve an almost complete recovery if treated properly during the first episode, compared to only about 70% when treated during a second or third episode, this approach requires lower doses of medication.

EPICC who are now seen as one of the foremost services, world wide, has developed GP guidelines to support early intervention programmes, the document reflects the

experiences they have gained and advocates doctors, teachers, parents and others should be “sensitized” to look for the sometimes prolonged duration of symptoms that lead up to the actual psychotic episode. These symptoms could include depression, anxiety, withdrawal, unusual concerns about bodily functions and sudden deterioration in school performance.

The North Birmingham IRIS initiative, which is recognised as a National Beacon Service was formed to promote early intervention and improve partnership between primary and secondary care. The government’s service implementation guidelines for early intervention are based on the IRIS clinical and service guidelines, whose core principles include:

- A youth and user focus.
- The importance of early and assertive engagement.
- The embracing of diagnostic uncertainty.
- Treatment to be provided in the least restrictive and stigmatising setting.
- An emphasis on social roles.
- A family-oriented approach

The service views the future care for young people with psychosis in a wider context of good mental health care which hinges on confident, well trained professionals and care- givers who are able to work autonomously, and capable of communicating and developing the networks of care and support around individuals and their families where they live. Gaining good mental health is more than just health and social care : systems of care relying solely on drugs and containment will fail to meet real needs of their clients if they do not attend to supporting jobs, housing, social networks, etc.

Distinctions between Primary, secondary and specialist disciplines become increasingly meaningless if we are serious about caring for people in their own communities. Birchwood et al (2000) believes there is a real need to improve access and that it will only come about by primary and secondary care radically reviewing its approach. The current specialist service configurations- separation of child and adolescent services from adult services at the crucial age when psychosis tends to develop creates obvious difficulties.

In concluding this section of the report it is clear that the evidence implies that intervention early in the development of psychosis may lead to complete, or almost

complete, recovery in a much larger proportion of patients than is currently the case. The beneficial effects of early intervention are supported by outcome studies that show that the greatest decline in functioning occurs in the first few years of the illness. A longer period of illness is associated with increasing negative symptoms and cognitive and behavioural deficits. Medical and psychosocial interventions may be more effective when newer antipsychotics are used at a relatively early stage. The combination of better tolerance and greater brain plasticity associated with the new drugs could render the patient more amenable to psychosocial interventions.

#### **4.0 Background to and structure of the Audit**

The IRIS audit tool was chosen used as it includes a number of assessment devices to assist in the auditing of services for individuals with a first episode of psychosis.

The tool is not exhaustive nor can it serve as a 'stand alone' procedure; it includes a number of useful instruments to support an audit strategy linked to the IRIS guidelines ( see appendix 1) and includes:

- Duration of untreated psychosis and pathways/obstacles to care
- Engagement in services and use of the Mental Health Act
- Treatment and care received

The audit of the pathways for young people from the onset of psychosis to the engagement with specialist treatment is examining 12 cases presenting to secondary services with a first episode of psychosis. The inclusion criteria were those individuals aged between 18 to 35 who had a diagnosis of schizophrenia or related disorder (ICD 10). The pathways to care audit used first time admission to hospital with psychosis as a starting point. This approach was chosen apposed to first contact with services.

Firstly, all new young people presenting to services were screened for any evidence of psychotic symptoms. This was done by requesting details of all first episode admissions from the information services department, then the medical records were examined and key workers were contacted.



The records were used to gather data about what was happening to them and when changes began to occur e.g. social withdrawal, hearing voices. The key-worker was also asked about help seeking and concerns to identify who was instrumental in obtaining professional help, who expressed concern, and what the response was. The aim was to establish: (a) onset of psychosis (b) who responded to this and how and (c) who may have responded but failed to do so.

The aim of the interview with the key workers was mainly to clarify information already obtained, identify what prompted help seeking or avoidance and understand the effects on someone close to the person.

It also helps to establish which services have been offered e.g. occupational, social, psychosocial interventions, family support. The CPA level and plan is also identified. The aim is to understand what help is provided by secondary services is the person still engaged with services and are all needs met.

This type of retrospective audit process is not an exact science but it is likely to offer a reasonable understanding of the time and nature of the onset of psychosis as well as a list of people who were involved with the person and may have tried to engage services.

By analysing the data a chronological profile emerged about the pathway to care, by amalgamating the information the case profile is then appraised retrospectively for what could have feasibly been done differently, given the benefit of hindsight and being mindful of best practice principles.

Examination of the pathways to care followed by people experiencing a first psychotic episode can enhance understanding of the barriers that confront them and help the development of a more responsive service.

## 5.0 Main Audit Findings

### 5.1 Introduction

This section is intended to present the main findings from the audit to assist senior mental health commissioners from the Mental Health Trust and PCT's to plan early intervention services for people with an emergent psychosis. The findings are summarised with both qualitative and quantitative data and brief vignettes being used for illustration and discussion.

- Overall the client group were young with average age of onset of 22years – 75% were under 24 years of age.
- The sample were equally divided between living alone and with either parent(s) or family.
- None of the sample lived with a spouse or partner.
- The education background of the sample:
  - 33% had GCSE's
  - 18% had A-levels
  - 49% had no qualifications
- None of the sample were employed, undertaking vocational training or in further education.

### 5.2 Duration of untreated illness (DUI) and use of the Mental Health Act (1983)

The average duration of untreated illness was 16 months (range 12 weeks-2 years). The duration of untreated illness is seen as the strongest predictor of outcome for first-episode psychosis and in this study did relate to the use of MHA but not to enhanced care planning following discharge.

Fig1

	<b>DUI&lt; 12mths</b>	<b>DUI&gt;12mths</b>
<b>MHA Use</b>	<b>50%</b>	<b>84%</b>

77% of the audit sample were detained under the MHA(1983) and this was found to be commoner if the person was a male or living alone. The strikingly high level of legal detention is comparable to other studies, and probably represents the norm.

The DUI is seen as the strongest predictor of outcome for first-episode psychosis and in this study did relate to the use of MHA but not to enhanced care planning following discharge.

### 5.3 Service Response

All the people in the study were discharged from hospital on the Care Program Approach (CPA) and offered outpatient appointments with a Consultant Psychiatrist.

33% received Enhanced CPA and,

67% Standard CPA.

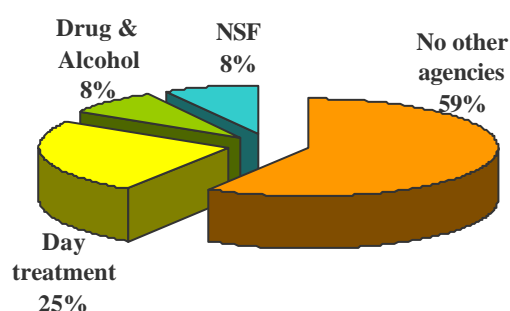
The CPA, when working effectively should ensure a multidisciplinary approach to meeting the needs of the client and family. Use of the Care Programme Approach (CPA) for all the cases in the study suggests that continuing contact with secondary mental health services is not an area of concern, this may not be the case. The unclear rationale for allocation to either enhanced or standard CPA, and the particular age group of the sample might be reasons for problematic and unsustainable engagement with the youth culture.

All were referred to their locality CMHT and allocated a CPA care co-ordinator/key worker. Of these 75% received a Community Psychiatric Nurse (CPN) and 25% a Social Worker (SW).

- 25% were also referred to Day Treatment Services
- 8% to Drug and Alcohol Services and
- 8% had support from The National Schizophrenia Fellowship.

### 5.4 Fig 2 Agencies involved at Discharge

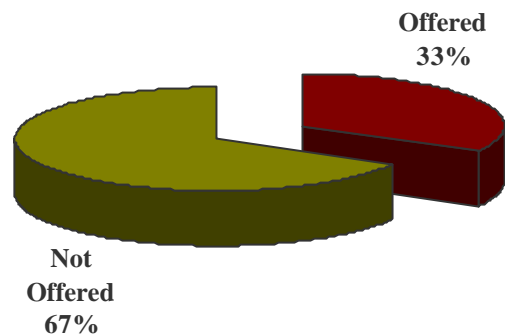
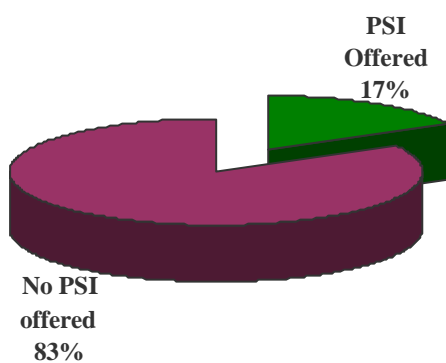
**Over half (59%) had no other agencies involved.**



Of the 12 cases studied only 2 were offered psychosocial interventions(PSI) and in only 4 cases did the key worker engage both the client and family in psycho-educational work. Only one key worker had a formal qualification in PSI.

**Fig 3 Psycho-social Interventions**

**Fig 4 Family Work**



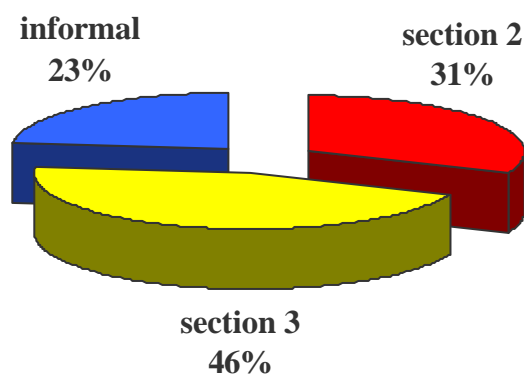
**5.5 Use of Mental Health Act, 1983 (MHA) and the Care Programme Approach (CPA) in first episode psychosis**

Out of the sample, the following details summarise the use of the MHA (1983) and the CPA:

- 77% were detained and of these:  
 31% were detained under Section 2  
 46% were detained under Section 3

**Fig 5 Mental Health Act use**

23% Informal Detention under the MHA (1983) was commoner if the person was a male or living alone.



With the high rate of formal admissions one would expect to see an associated rate of individuals receiving Enhanced CPA. Of the sample:

- 33% received Enhanced CPA and,
- 67% Standard CPA.

The CPA, when working effectively should ensure a multidisciplinary approach to meeting the needs of the client and family. Use of the Care Programme Approach (CPA) for all the cases in the study suggests that continuing contact with secondary mental health services is not an area of concern, this may not be the case. The unclear rationale for allocation to either enhanced or standard CPA, and the particular age group of the sample might be reasons for problematic and unsustainable engagement with the youth culture. The audit set delivery of the Care Programme Approach (CPA) as a universal standard for this group, and this was achieved. This is surprising as many young people are seen as reluctance to participate, and professionals risk possible disengagement by pressing the CPA arrangement.

The audit revealed some quality service responses reflecting proactive interventions with a well-integrated service between primary and secondary care, and which responded promptly to failing capacity and family concern. This contrasts with cases showing a more reactive response to crisis following on failures to engage earlier. This was through failures in primary care, failures in secondary care and both primary and secondary failures combined.

The frequent resort to compulsory hospital admission (77%) is evidence suggestive of the fact that this client group were not readily engaging early with current services, resulting in a tendency to engage when in crisis.

The long DUI reported here suggests that current practice is not using either CPA or MHA to facilitate engagement in the critical early phase. Ideally all people experiencing a first episode of psychosis and their families would be assertively engaged and supervised within an assertive community/outreach model.

The NSF sets a standard (4) that all mental health service users on CPA should:

- receive care which optimises engagement, anticipates or prevents a crisis, and reduces risk
- have a copy of a written care plan which:
- includes the action to be taken in a crisis by the service user, their carer, and their care co-ordinator
- advises their GP how they should respond if the service user needs additional help
- is regularly reviewed by their care co-ordinator
- be able to access services 24 hours a day, 365 days a year.

### 5.6 Medication on discharge

3 cases were prescribed typical antipsychotic medication (injection),

2 cases Depixol 40mg IM 2/52,

1 case Clopixol 200mg IM 2/52.

9 cases were prescribed atypical antipsychotic medication (tablets)

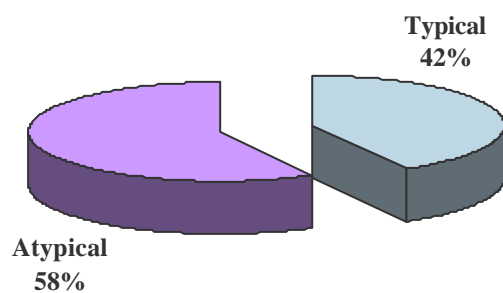
2 cases Amisulpride, 1 taking 300mg bd and 1 taking 150mg bd.

2 cases Risperidone, 1 taking 2mg bd and 1 taking 3mg bd.

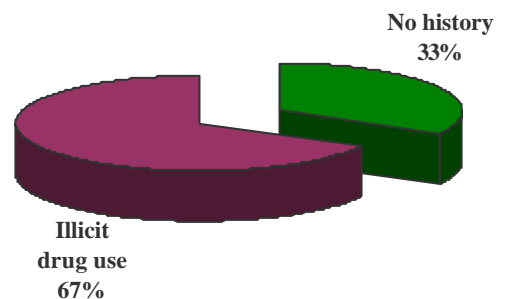
3 cases Olanzapine, 2 taking 15mg and 1 taking 20mg.

2 cases Quetiapine, 2 taking 150mg bd.

**Fig 6 Neuroleptic Treatment**



**Fig 7 Illicit Drug Use**



### **Medication concordance**

5 cases noted problematic issues relating to poor compliance with prescribed anti-psychotic medication.

1 refused to take medication

4 required regular monitoring and supervision

The National Institute of Clinical Excellence (NICE) now recommends newer antipsychotic drugs as one of the first line options to treat people

### **Co morbidity**

Prior to admission a small number of cases had been prescribed anti-depressants by their GPs. Whilst there was a strong indication that drug misuse had occurred prior to psychosis emerging specific details were lacking.

### **5.7 POINTS OF FIRST CONTACT AND PATHWAYS TO CARE.**

The report refers to those people involved in the pathway to care as ‘pathway players’. Each pathway player contact can be described as an opportunity for assessment of need. Ideally the person who is ‘point of first contact’ should identify the mental health needs early, enable prompt assessment, which will in turn lead to effective treatment and complete the pathway to care. This ideal is rarely achieved in any service and there are often a number of people involved before skilled assessment and successful engagement is finally obtained. The following was found:

- The average Duration of Untreated Illness (DUI) was 16 months (range 12 weeks - 2 years).
- Living alone predicted a longer pathway to care. There was a relationship between DUI and isolation (although with small numbers this was not subject to statistical analysis).
- Successful engagement was unlikely without the combined assertiveness of several ‘players’.
- Points of first contact could include a wide range of agencies, including primary care, during the period of emergent and untreated psychosis

Fig 8 shows that the number of pathway players involved in admission ranged from 3 to 12, with a mode of 5, suggesting multiple opportunities for engagement.

The graph represents simply the number of different people involved, and not how many times a particular pathway player was involved (e.g. the GP may have been consulted on several different occasions over the period of untreated illness, but would be recorded as a single player in this graph).

Only 1 adult accessed hospital admission via a routine out patient appointment and in that case there were only 3 pathway players – household, General practitioner and psychiatrist, which is the ideal pathway to care.

Types of pathway players that were involved in the 12 cases; the number represents the number of cases in which they were involved:

**Fig 8 Pathway Players in Wakefield and Pontefract Audit**

<b>PATHWAY PLAYER</b>	<b>% OF CASES</b>
<b>Psychiatrist</b>	<b>100%</b>
<b>Family member/friends</b>	<b>75%</b>
<b>General Practitioner</b>	<b>58%</b>
<b>Community Psychiatric Nurse</b>	<b>42%</b>
<b>A+E</b>	<b>25%</b>
<b>Police</b>	<b>17%</b>
<b>Police Surgeon</b>	<b>8%</b>
<b>Ambulance Staff</b>	<b>8%</b>

\*Social work staff excluded due to mandatory involvement with Mental Health Act processes

The commonest pathway players were:

- the family
- the GP
- A+E
- the CPN.

(The psychiatrist is in part an artefact of the nature of case identification in this study).



## 5.8 Case Vignettes

This section uses case vignettes to illustrate the variety of differing presentation and access into services.

Over half had their family GP as their first point of contact. For example:

Below are several examples of the differing pathways in to care:

- Craig had been behaving oddly since leaving school. Friends suggested that he might be on drugs, but he always denied taking illicit drugs and refused all encouragement to seek help from his GP. His parents became sufficiently concerned to request their GP to do a visit as he had repeatedly refused to go see the GP stating that he was fine and it was his parents that had the problem. The GP visited and requested an urgent psychiatric D.V, which resulted in a formal in-patient admission.
- James concerned parents took 20 year old son to see the GP who arranged an urgent assessment at the Out Patients Department with a psychiatrist. It was only after James had been in hospital for just over seven weeks that he disclosed that he had been hearing voices for over six months. James was detained in hospital under Section 2 of the MHA , which was later converted into a Section 3 of the MHA .
- The GP felt that Susan was suffering from a paranoid psychosis which was causing her and her family a great deal of distress, she was refusing to go to the hospital for further assessment, the GP urgently arranged a psychiatric DV and EDT assessment. Susan was then placed under a mental health act section at home and transported to hospital by the police.

The following case depicts a poor referral pathway and the ensuing problems arising from this:

- Kevin's parents had growing concerns for their son mental health due to his increasingly strange behaviour describing it as a total personality change, he stopped going out, lost contact with his friend, they felt unable to communicate with him, he never wanted to talk. They felt that they needed to seek help and assistance on their son's behalf after he refused to seek help himself. The GP, in

the absence of his own visit and assessment, referred him to the local CMHT requesting a mental health assessment. The routine referral was then allocated for assessment at the weekly team meeting, the assessing professional then made telephone contact with the family and asked to speak to Kevin order to arrange a visit, Kevin reluctantly took the call but declined the offer of a visit from the CMHT stating that he had never felt better and did not know what all the fuss was about. The telephone contact was fed back to the GP and no further action was taken. This happened on three separate occasions over an eighteen month period when Kevin's parents had contacted their GP explaining their concerns. Only on the fourth request did the GP visit and assess Kevin at his home, following which he arranged an urgent home assessment by a consultant psychiatrist which resulted in a formal admission to hospital for Kevin who was later diagnosed with 'paranoid schizophrenia'.

This case highlights several missed opportunities and barriers to collect information from community services. Several cases from the audit provide examples of good recognition by concerned family or professionals and assertively seeking help.

## **6.0 Conclusion and Recommendations**

In conclusion the National Service Framework (NSF) clearly highlights primary care access in Standard two:

Any service user who contacts their primary health care team with a common mental health problem should:

- have their mental health needs identified and assessed and be offered effective treatments, including referral to specialist services for further assessment, treatment and care if they require it.

This highlights 'points of first contact' in terms of awareness and empowering access to specialist assessments in low stigma settings. A major theme is developing joint guidelines for referral between primary and secondary care for more serious mental illness. This report supports the recommendation that people experiencing their first episode of psychosis and their families are regarded as a priority group that deserve specialist service responses.

The NSF Standard three states that; any individual with a common mental health problem should:

- be able to make contact round the clock with the local services necessary to meet their needs and receive adequate care
- be able to use NHS Direct, as it develops, for first-level advice and referral on to specialist help-lines or to local services.

The use of NHS Direct, and development of local protocols in supporting 'points of first contact' for access in difficult circumstances, such as out of hours, or where the route is unclear or inaccessible, should ensure staff are able to respond to the needs of this client group .

Primary care has to tackle the dilemma of separating a relatively unusual event for any one GP (typically two or less patients with first episode psychosis per year) from much commoner 'alarm-bell' symptoms. Pessimistic attitudes of GPs towards psychosis and the difficulties of accessing secondary services have been highlighted in other studies Copolov (2001).

Raising awareness, training of skills and challenging attitudes are essential and achievable. It may be more useful to develop training towards dealing with the critical period, when known cases are supported in the first few years of their illness, which could increase the relevance and numbers for Primary Care.

Primary care is not just about GP's. There are other agencies working in the community such as social workers, teachers, youth services, police and probation services each with their own needs for training, and for referral policies whether that be via the GP or direct to the specialist assessment.

Planning should take account off the breadth of potential 'points of first contact' in primary care and the wider community.

This retrospective audit study provides an exploration of some of the obstacles that prevented earlier and effective interventions for young people with developing psychosis.

The study is an examination of first episode psychosis in the local health district with a relatively geographically stable population and health services, and low ethnicity compared to the several studies that exist describing inner city experiences.

Service development requires a radical re-think of current approaches one that recognises the potentially serious and debilitating nature of psychotic illness and that it is often the social consequences of psychosis which are the most damaging.

A service model with a greater emphasis placed upon the adoption of best practice, the building of new professional relationships and partnerships as well as the adoption of a recovery model which puts clients needs, aspirations and lifestyle at the centre of all planning is therefore strongly recommended.

A combination of expert specialist treatment and models of care which focus on the psychosocial needs of service users is required if we are to significantly improve individuals' experience of psychotic illness and achieve genuine improvements in long term outcomes.

Three principle requirements emerge for changing services given to young people with psychosis and their families. These are:

- Improved primary care knowledge and skills regarding early detection and the value of evidence-based interventions in the early phase of psychosis,
- More acceptable secondary care responses for young people, and
- Better integration between primary and secondary care.

To preserve anonymity names and genders of the clients and family members and some of the social details have been altered. An audit of the ability of the family and community, of primary and secondary care, to respond to these concepts may enable service providers and commissioners to alter the pathways to care, and to reduce the impact of psychosis in Wakefield and Pontefract.

Integral to the reports recommendations is the promotion of a dynamic and on-going multi-disciplinary audit and the development of a steering group to lead the audit cycle.

The core data that will require regular auditing includes:

- Duration of untreated illness.
- Time lag between presentation to any pathway player and receipt of neuroleptic therapy.
- Family engagement in services.
- Numbers of young psychotic people entering the service annually - and separation of correctly diagnosed, false positives and false negative cases, ascertained at twelve months after entry, acknowledging that definitive diagnosis may not occur in the first year.
- The numbers of young psychotic individuals who progress to make good recovery, with a subsequent analysis of the local barriers and boosters that aide this process.

Following the governments commitment to the development of early intervention services, it is envisaged that local approaches will now start to develop rapidly across the country.

Wakefield and Pontefract has already shown its commitment to providing a first class service for young people with psychosis and their families by supporting this Health Action Zone project and further by its planned undertaking of a major innovative research project, titled

**First episode of psychosis in Wakefield and Pontefract: incidence, inception to care and out come. (see Appendix 2)**

The aim of the project is to establish a firm understanding and empirical base for health improvement in young people and their families experiencing psychosis for the first time. In particular, the inception rate, geographical distribution, pathways to care, content of care, engagement with services and outcome over a two year period. Based upon the number of deprived localities, it is anticipate the rate of first onset psychosis in this district (population approx. 330,000) to be between 50 and 70 cases each year.

The project will be at the forefront of the developments in Early Intervention within the Northern and Yorkshire region and in accordance with Department of Health directives, it will establish an empirical sound evidence-base for the development of a local early intervention service for first episode cases of psychosis.(DoH 2001).

## APPENDIX 1

### **10- Point Service Specification based on Regional IRIS Strategy guidelines:**

**Strategy 1:** Early detection and assessment of psychosis as an essential component of early intervention.

- Multi-disciplinary audit of pathways to care can reveal the variation in duration of untreated illness, the variety of pathways to care (GP, Police, neighbour, church etc) and their relationships to the pathways: identifies training needs and potential service developments in community, primary and secondary services improves collaboration between primary and secondary care to promote early detection and treatment enables user and carer experiences to influence development Clinical guidelines for screening and referral. Inherent in this is a tolerance of diagnostic ambiguity and focus on dominant symptoms.
- Setting for initial assessment: non-stigmatising e.g. assessment at home or GP surgery.
- For some potential cases presence of psychosis will be initially unclear; keep three month 'watching brief, support as appropriate; those with an underlying psychosis are likely to progress within this time frame.

**Strategy 2:** A key worker allocated on referral of the case to 'stay with' the service user and family/friends through the first 3 years (the 'critical period') preferably within the assertive outreach model.

**Strategy 3:** A comprehensive assessment plan and collaborative assessment of needs should be drawn up, and driven by the needs and preferences of the user and his/her relative and friends.

- Incorporates assessment of mental state, vulnerability, psycho-social and social factors (see tool kit), involving the user and his/her family: reviewed at:  
6 weeks 3 months 2 years

**Strategy 4:** The management of acute psychosis to include low dose standard and atypical neuroleptics and the structured implementation of cognitive therapy.

- Clinical guidelines for use of neuroleptics should be agreed with explicit reference to regular review, dosages, side effect monitoring, treatment resistance and use of newer atypical neuroleptics (Refer to Regional IRIS strategy and toolkit for detailed consideration of pharmacological approaches).

- Guidelines should include various treatment strategies including: psychosocial interventions; managing positive and negative symptoms; relapse strategies; cessation of medication.

**Strategy 5:** Family and friends actively involved in the engagement, assessment, treatment and recovery process:

- Engagement of the service user should embrace the family, within one week of presentation so that crisis support, debriefing and the family's perspective can be gained.
- This initial contact should be at their home and a 'debriefing' session, giving the family opportunity to 'tell their story' about the build up to psychosis and to give vent to their feelings.
- Straightforward psychoeducation and support, individually and in groups should be provided.
- Psychoeducation Family Intervention should be available focusing on:
  - Ongoing relationship problems in the family
  - Unresolved loss and despair in key relatives
  - Problems of coping with psychosis-related behaviour at home.
- Family and friends should, with the agreement of the service user, be part of ongoing review.

**Strategy Six:** Relapse prevention/minimisation and for treatment resistance should be implemented to embrace vulnerability factors, prophylaxis, and early detection /intervention.

### **Relapse Prevention**

- Users and families should be informed about the risk for relapse and what factors are within their control.
- Relapse risk assessment should form part of the ongoing assessment progress and embrace:
  - Vulnerability (untreated psychosis, previous exacerbations)
  - Prophylaxis: Utility of and adherence to medication regimes
  - Stressors both acute (life changes, cannabis abuse) and long term (intrafamilial stress, unstable life patterns).
- An individualised, shared and documented relapse prevention plan should be developed and rehearsed with the user and social network. This should include:
  - Individualised signs of relapse ('relapse signature')
  - Development and rehearsal of a linked 'relapse drill' involving, where appropriate, a targeted and time limited neuroleptic medication
  - An active relapse monitoring procedure

- The experience of relapse/exacerbation should be viewed as an opportunity to learn about the relapse signature and operation of the relapse prevention procedure.

## **Treatment Resistance**

The continued experience of psychotic symptoms within 6 months of first treatment suggests that such symptoms are likely to continue. The review at this point should declare the presence of drug resistant symptoms and determine an appropriate strategy.

Trial of atypical neuroleptics with such as Clozapine should be considered.

Cognitive therapy can reduce drug resistant symptoms and should be considered.

Teaching clients to deal with and cope with such symptoms to minimize distress may be required

### **Strategy 7:**

- Facilitate clients' pathways to work and valued occupation during the critical period, to include:
  - Assessment of clients best ever educational/vocational functioning work experiences and employment aspirations as part of the assessment plan and reviewed regularly.
  - User led vocational/educational training program; where possible implemented in conjunction with e.g. Training and Enterprise Council and other relevant agencies.
  - Job training opportunities within mental health services where appropriate; tapping service users' invaluable experience of psychosis and of mental health services, and using their employment in services to provide an important stepping stone.

**Strategy 8:** Ensuring that basic needs of everyday living are met and reviewed regularly, which:

- Makes available appropriate accommodation of the users' choice.
- Assesses the individual's eligibility for benefits, grants etc.
- Facilitates access to specialised help as needed: legal aid, social work, CAB etc.

**Strategy 9:** Assessment and treatment of 'co-morbidity' in conjunction with that for psychosis addressing:

- Problematic substance misuse, depression / suicidal thinking, social avoidance and intrusive memories linked to the psychosis, and assessed regularly.
- Opportunities for personal counselling on matters concerning the development of and adaptation to psychosis. This might take the form of a structured recovery program (see tool kit), including an opportunity to form alliance with others facing similar difficulties.



- Specialised help for substance misuse including information about the risks for relapse associated with heavy cannabis use.

**Strategy 10:** Locally promoting positive images of young people with psychosis.

A community education programme to emphasise the treatability of psychosis and counteract negative social attitudes regarding psychosis. This should be targeted at the professional and voluntary sectors likely to encounter young people with psychosis; for example student health services, schools, police, homeless agencies, and religious / cultural organisations.

- Local media - form positive relationships with journalists on local newspapers, radio and television, in order to correct mistaken beliefs about psychosis

## APPENDIX 2

### FIRST EPISODES OF PSYCHOSIS IN HALIFAX, HUDDERSFIELD, NORTH KIRKLEES, WAKEFIELD AND PONTEFRACT: INCIDENCE, INCEPTION TO CARE AND OUTCOME

#### Brief Outline of the Early Intervention (EI) Research Project.

- The project forms an integral part of the strategy to develop new services. The design will be an epidemiological inception to care cohort prospectively monitored for 24 months, of first episode cases of acute psychosis presenting to secondary mental health services.
- Information generated will provide accurate measures of the pathways into care, the duration of untreated psychosis (DUP), Mental Health Act use, the patient's interface with primary care and the treatments available.
- The cohort will be followed-up at inception (or baseline), 12 and 24 months from the onset of psychosis. Measures to be taken will determine key features of this clinical population essential to EI service planning and provision, including:
  - the extent of engagement with services and numbers lost to follow-up, including compliance to treatments,
  - readmission/relapse rates, including number of relapsers lost to follow-up,
  - the proportion of patients detained under the Mental Health Act,
  - treatment resistant symptoms,
  - Quality of Life and psychological reaction to psychosis and adjustment, including depression and suicidal thinking and
  - family/carer issues including social network support and Expressed Emotion.
- The project will also form the basis of an R&D framework to underpin this new service.
- A final report to the Commissioners will be provided including recommendations about the delivery of services.

#### The Research Team

- Professor Max Birchwood, Service Director, Early Intervention Beacon Service and Director of Research & Development (Northern Birmingham Mental Health NHS Trust) and Professor of Clinical Psychology (University of Birmingham) linked to the Interdisciplinary Centre for Mental Health. He is the lead researcher for the project.

- **Professor Birchwood has an international clinical and research reputation and has been a key figure in the development of innovative treatments for people with psychosis in the areas of family work, relapse prevention, cognitive-behavioural treatments for drug-resistant symptoms and postpsychotic depression and suicide. In 1996 he pioneered the development of the North Birmingham 'Beacon' Early Intervention Service, the first such service in the UK, and is a founding member of the IRIS (Initiative to Reduce the Impact of Schizophrenia) group, which is dedicated to the development of effective EIS practice throughout the NHS.**
- **Dr Zaffer Iqbal, Senior Clinical Research Fellow, University of Birmingham, is the locally based research manager for the project and a committee member of IRIS. He is responsible for all the day-to-day aspects of the project, including ethical submissions, training, liaising with local practitioners (primary and secondary services) and will advise and support service development planning alongside senior management. Dr Iqbal has recently produced a protocol in conjunction with the Child and Adolescent Mental Health Services, which will allow the project to map the nature of psychosis in patients between 14 and 17 years inclusive.**
- **The project commenced in Calderdale and Kiveton Park in April 2001 and is currently comfortably exceeding the predicted recruitment numbers. Data collection is set to start in Wakefield / Pontefract in May 2002. Steven Coles, a full-time Research Associate from the University of Birmingham, is based locally with Dr Iqbal and responsible for all follow-up contact. Data collection in Wakefield / Pontefract will be supported by the involvement of Michael Brennan, the local project CPN and the appointment of an assistant psychologist.**
- **Two research groups (adult and CAMHS), which involve senior clinicians, managers and commissioners from all four districts of the Trust, have been established to provide local steering for the research.**

## **APPENDIX 3**

### **The Newcastle Early Psychosis Declaration**

#### **Ordinary Lives....**

#### **Early Intervention and Recovery for all Young People with Early Psychosis**

**June 26th - 27th 2002**

#### **The Newcastle**

#### **Early Psychosis Declaration**

**On June 26th and 27th 2002 over forty service users, family members and expert practitioners from across the UK met with representatives from the World Health Organisation, IRIS (Initiative to Reduce the Impact of Schizophrenia) and Rethink in Newcastle Upon Tyne, England, to agree and sign up to this declaration.**

**The Newcastle Declaration sets out to attract and encourage practitioners from a wide range of health, social, educational and employment services to reflect on how they can better contribute to supporting young people with psychosis, their families and their friends. In proposing a series of standards the declaration encourages the setting of expectations from young people experiencing psychosis and their families that will influence the development of better services.**

**This document sets out a clear vision, some core values, and some actions required to achieve early intervention and recovery for all young people experiencing psychosis.**

#### **Background**

**The approach has been modelled and inspired by the original St Vincent Declaration for Diabetes (1989). The latter was released in St Vincenzo, N.Italy by a group of service users, clinicians and senior health civil servants from a number of European countries. With the strong support of the British Diabetic Association in the UK and the WHO internationally the St Vincent declaration has transformed diabetic care. A trip to the internet confirms its phenomenal achievement.**

#### **The Vision**

**A fundamental objective of the Newcastle Declaration is to generate optimism and expectations of positive outcomes and recovery so that all young people with psychosis and their families achieve ordinary lives.**

**This declaration promotes timely and effective interventions for young people with early psychosis and similarly, appropriate support for their families and close friends. Adoption of these standards will provide a benchmark for services to measure their success against.**

**Finally the declaration asks for a much wider understanding across society about psychosis and the importance of getting help early. Its recommendations do not confine themselves to health interventions but also challenge stigmatising and**

**discriminatory attitudes so that young people are not disadvantaged by their experiences and are truly included in their local communities.**

## **The Values**

**The Newcastle declaration promotes the belief that young people with psychoses and their families can be encouraged and indeed should expect to lead ordinary lives within their communities.**

**The declaration also promotes recognition of the immense contribution to care made by family and friends.**

**Services should:**

**actively partner young people, their families and friends to place them at the centre of care and service delivery**

**use therapeutic approaches that are known to work**

**be sensitive to age, phase of illness, gender, sexuality, cultural background and spiritual beliefs**

**The Actions - a series of 5 year targets**

**We have chosen the following five priority themes:**

**5 year target for Raising Community Awareness about the importance and opportunities for earlier detection and improved management of psychosis.**

**The declaration calls for a significant improvement in public understanding about psychosis:**

- Every 15 year old should be equipped by mainstream education to understand and access help for psychosis**
- Psychosis awareness training should be provided for teachers, community agencies and the general public**

**5 year target for Improving Access and Engagement:**

**a. Access to comprehensive support programmes provided by individuals and teams**

**with specialised skills in the detection and treatment of early psychosis and in supporting the needs of young people**

**b. Access to a full range of primary healthcare services for every young person with early psychosis**

**The declaration calls for early access and non traumatic engagement with services:**

**\* Time to access support from the onset of psychosis (Duration of Untreated Psychosis) should on average be less than 3 months and not exceed 6 months**

**\* Walk in responsive services should be available**

**\* Every primary care site will know how to respond effectively to early psychosis**

**\* The use of involuntary treatment in early psychosis should be reduced by 50%**

**5 Year Target for Promoting Recovery and Ordinary Lives**

**The declaration calls for a right to recovery and social inclusion and supports the importance of personal, social, educational and employment outcomes:**

**\* 60% of individuals should be in mainstream work, training or education or have education and employment rates similar to their age and gender peers**

**\* The days lived with disability should be reduced by 50%**

- \* **Suicide rates should be reduced by 50%**
- \* **90% of consumers should be satisfied with their educational, employment and social outcomes**

**5 Year Target for Family Engagement and Support to access information and social, financial, practical and emotional support**

**The declaration calls for recognition, training, support and involvement of families and close friends:**

- \* **First contact with families or others who support the individual will be within 4 weeks**

- \* **Families and close friends will receive effective services appropriate to their needs**

- \* **90% families will report that they feel respected and valued as partners in care**

**5 Year Target to provide Practitioner learning to develop their understanding of early psychosis and effective support for individuals with psychosis, their families, friends, working associates and the health care team**

**The declaration calls for appropriate training and support for a range of health and community professionals from a wide variety of agencies:**

- \* **Care for young people with early psychosis should form a routine part of the training curricula of all generalist and specialist health and social care practitioners**

- \* **All staff working in primary care and community support agencies including police, criminal justice, ambulance, housing and welfare agencies should have received education about psychosis**

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